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OXFORD REGIONAL TRAINING COURSE IN CLINICAL PSYCHOLOGY

Doctorate in Clinical Psychology

***An Investigation into the Motivation Underlying
Restricted and Repetitive Interests and Activities
in Autistic Spectrum Disorders***

Hilary Buckby

A thesis submitted in partial fulfilment of the requirements of the
Open University for the degree of Doctor of Clinical Psychology

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**THE APPENDICES ON PAGES 122-146 HAVE
BEEN EXCLUDED AT THE REQUEST OF THE
UNIVERSITY**

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Section 1

Introduction

Section 1: Introduction

1.1 Overview

The aim of this study is to investigate the motivation underlying restricted and repetitive interests and activities in autistic spectrum disorders (ASD). This section provides the context for the study by discussing: the definition and description of ASD; current psychological theories of ASD; possible theories of restricted and repetitive interests and activities; and the rationale and hypotheses that form the basis of the study.

1.2 Autistic Spectrum Disorders

Autism was first identified in 1943 by Leo Kanner (cited in Trevarthen, Aitken, Papoudi & Robarts, 1998, pp. 5). Just a year later Hans Asperger (cited in Trevarthen, Aitken, Papoudi & Robarts, 1998, pp. 5) identified a similar (though he claimed distinct) group of children. Whilst Kanner's work sparked immediate interest, Asperger's syndrome only came to attention in the 1980s. Since then the relationship between the two disorders has been debated.

DSM IV incorporates "Autistic disorder" and Asperger's Disorder within the category of Pervasive Developmental Disorders. Diagnosis of Autistic Disorder requires identification of: a qualitative impairment in social interaction; qualitative impairments in communication; and restricted and

stereotyped patterns of behaviour, interests and activities. There is usually some degree of learning disability. Although Asperger's syndrome is classed as a separate disorder within DSM IV, the only difference in diagnostic criteria is that there should be no clinically significant delay in language, cognitive development or self-help skills. Despite the lack of language delay in Asperger's syndrome, there are still qualitative communication impairments. The overlaps between the two disorders seem greater than the differences and the distinction requires careful diagnosis according to strictly applied criteria. It is doubtful whether this is adhered to in clinical diagnosis or research.

Many clinicians prefer to think of autism and Asperger's syndrome as part of a continuum; Wing (1996) has coined the phrase "Autistic Spectrum Disorders" (ASD). Throughout this piece of work the term ASD will be used. This is more a reflection of the inconsistency of usage within the literature and in clinical practice than a statement regarding aetiology or phenomenology.

The difficulties in social interaction, communication and imagination in ASD are described as the "triad of social impairments" (Wing & Gould, 1979). Studies of social behaviour in ASD suggest that it is a chronic deficit, although changing with development (Baron-Cohen, 1988). In adolescence and adulthood individuals may desire friendships and make social approaches, but are still unable to be socially responsive to others (Rutter, 1978; cited in Rutter, 1983, pp 525).

Language ability varies considerably, from mutism to possession of accurate and sophisticated grammar and vocabulary. The key problem is with language *use* or pragmatics (Landry & Loveland, 1988) for example intonation, use of expressive gestures and understanding social "rules" in conversation (Baltaxe, 1977, cited in Baron-Cohen, 1988, pp. 385; Tager-Flusberg, 1997).

Impairments of imagination are first noticeable in early childhood. Children with ASD lack symbolic play and tend to stick to rigid routines and manipulation of objects: spinning wheels, switching things on and off, smelling or licking objects (Roeyers & van Berckelaer-Onnes, 1994). With development, these manipulative activities may cease, but rigidity and lack of creativity remain.

Repetitive stereotyped activities are the focus of the current research. These might involve, at their simplest level, repetitive searching for particular sensations - tasting, smelling, staring at lights, shiny objects or spinning things; however they may extend into the formation of elaborate routines (such as arrangements of objects or following particular routes). In those who are more able the repetitive activities often take the form of a fascination with a particular subject - motorway routes, numbers on lamp-posts, science fiction characters. The interest generally involves collecting, memorising facts and talking about the subject (Wing, 1996).

Having defined and described ASD, the following sections will focus on possible explanations for its features, in particular restricted and repetitive interests and activities; firstly by examining theory and research applied specifically to ASD, then considering other relevant fields.

1.3 Psychological Theories of Autistic Spectrum Disorders

This section discusses the three most current psychological theories that have been proposed to account for features of ASD.

1.3.1 Theory of Mind

Baron-Cohen, Leslie & Frith (1985) suggested that people with autism lack the ability to infer the mental states of other people and to understand that these states can predict action - "theory of mind" (ToM).

Studies based on this theory have investigated children's understanding of the concept of *belief*, often by presenting scenarios which require realisation that another person may hold a different (and possibly false) belief to one's own. Children with autism show a lower success rate than control groups (e.g. Baron-Cohen, 1985; cited in Baron-Cohen and Swettenham, 1997, pp. 880), although around 20% do succeed. More complex tasks demanding the inference of "second-order" beliefs (e.g. Sally thinks that Sam thinks) reveal a lower success rate for children with

autism (Baron-Cohen, 1989a; Sparrevohn & Howie, 1995) and even for high functioning adults with ASD (Baron-Cohen, Joliffe, Mortimore & Robertson, 1997; Happé, 1994). However, Bowler (1992) found adolescents with Asperger's syndrome just as able to solve second-order ToM problems as control groups. This suggests that any ToM deficit is not absolute.

If one accepts that there is a ToM deficit in ASD, problems with pragmatic language skills and limited/unusual social interaction can be viewed as the product of an inability to understand the person who is being conversed or interacted with (Frith, 1996; Tager-Flusberg, 1997). However, ToM has not been applied directly to restricted activities and interests and it is difficult to infer how this feature could be explained by a lack of mentalising (Frith & Happé, 1994). One could consider these pre-occupations as a substitute for social relationships, but the question remains, why this particular substitute? ToM cannot answer this. The following two sections will consider other theories.

1.3.2 Executive Function Deficits

Ozonoff, Pennington & Rogers (1991) suggested that people with ASD have a deficit in "executive functioning", i.e. mental processes said to be located in the frontal lobes and including planning, goal-directed behaviour and inhibition of inappropriate and perseverative responses.

Hughes, Russell & Robins (1994) found that autistic participants had a significant deficit in set shifting and planning abilities. They related this to

Norman & Shallice's (1980) hypothesised "Supervisory Attentional System" (cited in Hughes, et al, 1994, pp. 489), without which behaviour would be triggered either by the environment (leading to distractibility and loss of control) or current activity (leading to response perseveration and difficulties with shifting mental set).

There is evidence to suggest that people with ASD have deficits in executive function processes (see also McEvoy, Rogers & Pennington, 1993; and Ozonoff, Strayer, McMahon & Filloux, 1994). Language and social interaction difficulties could stem in part from problems with flexibility - an inability to disengage from the immediate context and to inhibit inappropriate responses. Similarities have been drawn between the social behaviour of people with autism and those with frontal lobe damage - concrete language, lack of empathy and shallow affect (Damasio & Maurer, 1978; cited in Ozonoff et al, 1991, pp 1100).

Narrow interests and repetitive behaviours could be considered a perseverative pattern, deriving from an inability to shift responses and a lack of flexibility of thought and action. However, detailed application of the theory is as yet lacking. One difficulty is the lack of specificity of executive function deficits to autism. They are observed in many other conditions, including Parkinson's Disease, Tourettes syndrome, head injury and obsessive-compulsive disorder (Baron-Cohen & Swettenham, 1997). Sufferers of these conditions do not demonstrate autistic-like patterns of behaviour. This criticism does not exclude the possibility of a role for executive dysfunction in

ASD, possibly with co-occurring theory of mind deficits (Baron-Cohen & Swettenham, 1997). However, it seems that the executive dysfunction hypothesis itself is too broad to provide the specific explanation sought here. The following section describes an alternative.

1.3.3 Central Coherence Theory

Frith (1989) suggested that both abilities and deficits in autism could be accounted for by a cognitive bias. The theory proposes that whereas normal information processing pulls together different information and its context to construct meaning (Bailey, Phillips & Rutter, 1996), this “central coherence” is lacking or weak in ASD, resulting in fragmented information processing.

Evidence for a deficit in central coherence was taken initially from Shah & Frith's (1983) finding that children with ASD were significantly more skilled than control groups at deciphering “embedded figures”. In 1993 Shah & Frith found that children with ASD performed significantly better on the Block Design subtest of the Wechsler Intelligence Scales (Wechsler, 1974, 1981) relative to other subtests and to mildly learning disabled individuals of similar age and non-verbal IQ.

Though this evidence appears to support the theory of weak central coherence in its application to early perceptual or attentional processing (Happé, 1996), there is still the question of how higher functions such as communication and social interaction are affected. Frith & Happé (1994) suggested that theory of mind and central coherence are distinct processes,

the former accounting largely for the “triad of impairments” and the latter conferring advantages on tasks that require a focus on detail and disadvantages on tasks that require the integration of information with context.

The application of central coherence theory to restricted and repetitive interests and activities is not clear. If the interest or activity in question requires a focus on detail and a “piece-meal” approach to understanding or performance, then a weak central-coherence mechanism would be advantageous. However, while this might explain why individuals with ASD could be skilled at certain activities, it does not explain the motivation.

1.3.4 Summary

None of the foregoing theories offer an adequate explanation of motivation for restricted and repetitive interests and activities in ASD. The only one to address the question directly is the executive dysfunction hypothesis and it lacks specificity. If the theoretical and empirical work related directly to ASD does not provide a satisfactory answer is it possible to extrapolate from other fields of research? The following sections investigate this possibility by looking at the literature related to obsessive-compulsive disorder and hobbies in the general population.

1.4 Theories of Restricted and Repetitive Interests and Activities

1.4.1 Obsessive Compulsive Disorder (OCD)

On examination of the literature, Baron-Cohen (1989b) concluded that the terms obsession and compulsion are used in relation to ASD to describe repetitive, stereotyped actions; “resistance to change”; and repetitive interest in narrow subjects. Hollander (1997) even describes autism as “an example of the neurologic cluster within the OCD spectrum” (pp. 5).

1.4.1.1 Definition

The essential features of OCD are recurrent obsessions or compulsions (DSM IV). Obsessions are defined in DSM IV as “persistent ideas, thoughts, impulses or images that are experienced as intrusive and inappropriate and that cause marked anxiety or distress” (pp. 418). They are “ego-dystonic”, meaning that the individual perceives them as alien and out of their control.

Compulsions are defined as “repetitive behaviours or mental acts the goal of which is to prevent or reduce anxiety or distress not to provide pleasure or gratification” (pp. 418). Usually, the individual feels driven to perform the compulsion to reduce the distress that accompanies an obsession, or to prevent some dreaded event or situation. Compulsions are either excessive or not realistically connected to what they are meant to neutralise or prevent and may be overt or covert (deSilva, 1994).

In order to diagnose OCD it must be demonstrated that the individual has, at some point, recognised that his/her obsessions or compulsions are excessive or unreasonable (though this does not apply to children, and a person may be labelled as having poor insight). The obsessions or compulsions must cause marked distress and be time consuming (more than 1 hour per day) or significantly interfere with normal routine, occupational functioning or social activities/relationships.

If repetitive and restricted interests and activities in ASD are a form of, or closely related to OCD, what kinds of psychological processes might explain them?

Currently, the most prevalent psychological model of OCD is based on cognitive-behavioural theory.

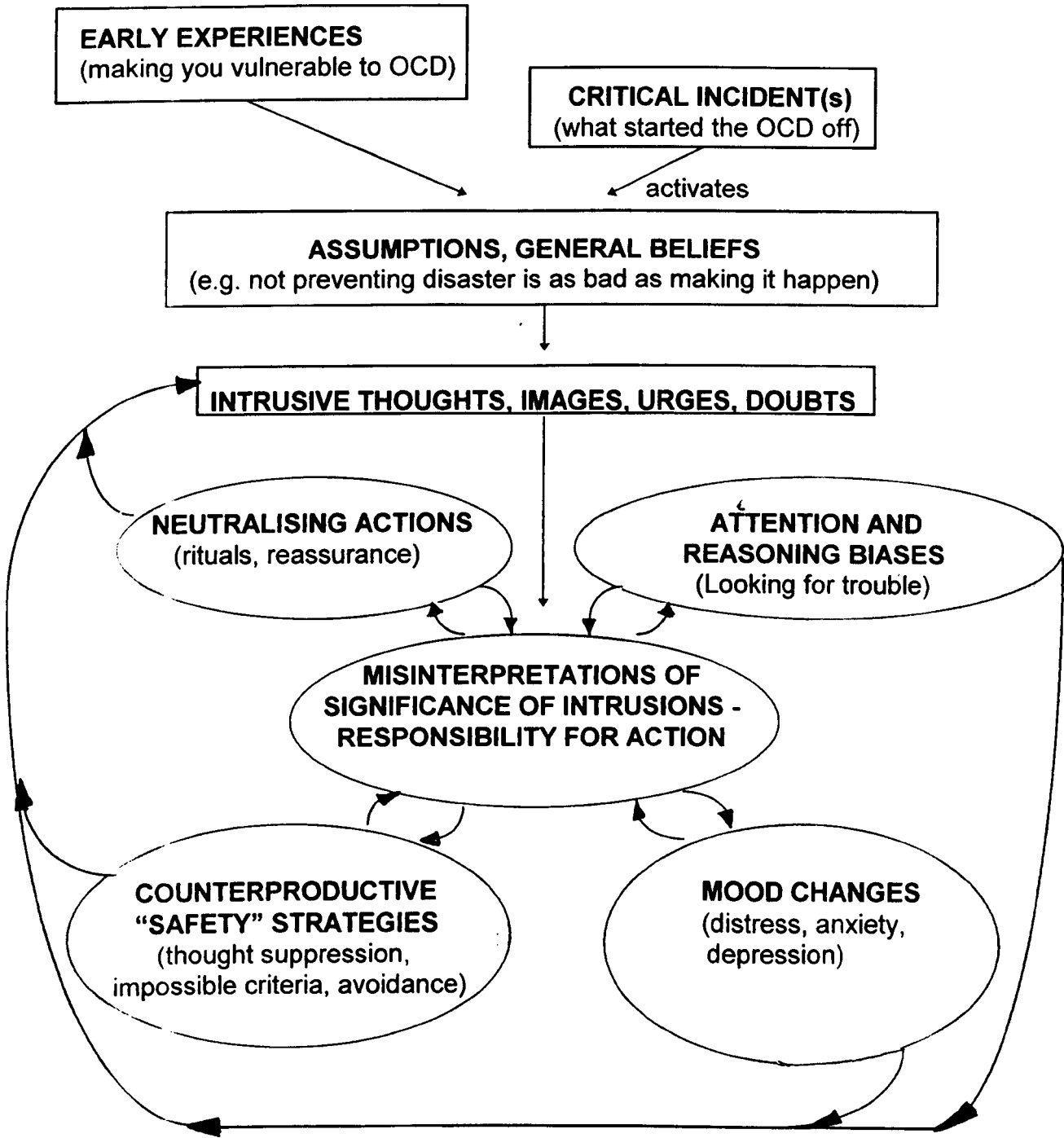
1.4.1.2 **Cognitive-Behavioural Model of OCD**

Figure 1 (page 13) provides a diagrammatic representation of this model. The cognitive-behavioural theory of OCD suggests that obsessional thinking begins with the sorts of intrusive cognitions (ideas, thoughts, images, impulses) occasionally experienced by all of us (Salkovskis, in press). The difference is that these intrusions are *misinterpreted*, specifically as an indication of *responsibility* for harm or for its prevention (Salkovskis, 1998; Salkovskis, Forrester & Richards, 1998).

This misinterpretation leads to discomfort, anxiety or depression. It also provokes increased attention on and accessibility of the intrusions. In response, the individual attempts to reduce the cognitions, or discharge their sense of responsibility. Strategies may include neutralising, compulsions, avoidance of situations related to the intrusive cognition, seeking reassurance (sharing responsibility) and endeavours to eliminate cognitions. These efforts are regarded by the person as exaggerated or senseless and may be resisted, but the urge may be too strong (Rachman & Shafran, 1998). Although this may provide some initial relief from anxiety, in the longer term it is counterproductive - increasing the salience and frequency of the original (and related) cognitions, and preventing disconfirmation of the feared consequence. This provokes a vicious cycle in which further anxiety and neutralising is likely (Salkovskis, Westbrook, Davis, Jeavons & Gledhill, 1997).

People who experience this cycle, it is suggested, are predisposed to certain interpretations owing to assumptions they have learned throughout their life (Salkovskis, 1998, pp. 44).

Figure 1: Cognitive-behavioural model of OCD
(taken from Salkovskis, Forrester & Richards, 1998; pp 58)



There is some evidence for this model. People who experience recurrent obsessions have been found to attach exaggerated significance to them (Freeston, Ladouceur, Gagnon & Thibodeau, 1993; cited in Rachman, 1997, pp. 794); responsibility assumptions and appraisals have been found to differentiate OCD patients from non-clinical and anxious controls (Salkovskis, Wroe, Richards, Morrison, Gledhill, Thorpe, Forrester & Reynolds, 1998; cited in Salkovskis, 1998, pp. 45). Lopatka & Rachman (1995) found that people with obsessional problems tend to think that the probability of misfortune increases when they are responsible and that only they can be held responsible for misfortunes over which they have no control. They also found that sense of responsibility could be experimentally manipulated and that decreases in perceived responsibility were followed by significant decreases in discomfort and urge to check.

Rachman (1997) suggests that a second cognitive-bias exists in OCD sufferers: **thought-action fusion (TAF)** (Rachman, 1993; Shafran, Thordarson & Rachman, 1996). This refers to two possible beliefs: the belief that having an unacceptable thought increases the probability that the unwanted event will occur; and the belief that having an unacceptable, repugnant thought is morally equivalent to performing the action itself. An inflated sense of responsibility can both contribute to the occurrence of TAF and be a product of it. Shafran, Thordarson & Rachman (1996) found TAF to be higher in obsessional than non-obsessional samples.

Symptoms of OCD are therefore ego-dystonic and interfere with social and occupational functioning. The purpose of behaviours attached to obsessions is broadly that of **harm-reduction**. To apply the OCD model to repetitive and restricted interests and activities within ASD, this ego-dystonia, interference and harm-reduction motivation must be demonstrated. Before considering the specific relationship between ASD and OCD, other elements of obsessional and compulsive symptomatology will be considered.

1.4.1.3 **Compulsive Hoarding**

Compulsive hoarding is generally considered to be closely related to or subsumed within OCD (Frost & Gross, 1993) and is defined by Frost & Hartl (1996) as the acquisition of, and failure to discard, possessions which appear to be useless or of limited value; interfering with daily activities and causing significant distress or impairment in functioning.

The cognitive-behavioural model of compulsive hoarding (Frost & Hartl, 1996) ascribes importance to:

- **Information-processing deficits:** including indecisiveness and an excessive sense of responsibility for harm.
- **Emotional attachment:** either owing to pure sentimentality or an association of the object with comfort and safety.
- **Behavioural avoidance:** of decision-making by saving possessions (Frost & Hartl, 1995; cited in Frost & Hartl, 1996, pp. 348).

- **Beliefs about the nature of possessions:** the necessity of maintaining control over possessions; responsibility for possessions; and the necessity of perfection.

There is some evidence in support of this model. Frost & Gross (1993) found hoarding tendencies in female undergraduates to be related to perfectionism and indecisiveness, as well as to measures of OCD symptoms. It was not clear that the hoarding was ego-dystonic; however, the hoarders often reported their behaviour to cause conflict with other family members. The most commonly reported motivation was that of possible future need for the objects. Frost, Hartl, Christian & Williams (1995) found that people with hoarding tendencies were very concerned about maintaining control over their possessions - they did not like others to touch, use or share them. There was strong support for the notion of elevated perceived responsibility in hoarders.

This model again draws out factors that one would need to identify to equate repetitive and restricted interests and activities in ASD with compulsive hoarding. Although the ego-dystonia associated with full-blown OCD is less evident here, there is evidence of distress caused by the behaviour, and by its interference in everyday functioning. There is also further evidence of the role of an elevated sense of responsibility for harm, and some suggestion of avoidance behaviour.

To continue with the discussion of obsessions and compulsions, it is useful to consider two final concepts: personality characteristics and “normal” obsessions and compulsions.

1.4.1.4 Obsessive-Compulsive Personality

If one considers obsessional and compulsive symptoms as a continuum, at some point a link with personality traits is possible. Obsessive-compulsive personality disorder (OCPD) is described in DSM IV as “A pervasive pattern of preoccupation with orderliness, perfectionism and mental and interpersonal control, at the expense of flexibility, openness and efficiency”. There is evidence to suggest a relationship between obsessive-compulsive traits and symptoms of OCD (Tallis, Rosen & Shafran, 1996). In a review of the literature, Summerfeldt, Huta & Swinson (1998) draw out dimensions of personality that appear to be linked with OCD, including trait anxiety, responsibility, indecisiveness and perfectionism. Frost & Shows (1993) found that, in non-clinical participants, indecisiveness was related to perfectionism and to obsessional thoughts, compulsive checking and hoarding.

This would suggest some personality characteristics to be associated with obsessions and compulsions. At a certain level these may be problematic (as in OCPD), or they may simply be sub-clinical tendencies of the individual. It may be that what is displayed in repetitive and restricted interests and activities in ASD is a tendency towards this “type” of personality (possibly including perfectionism and indecisiveness) rather than a full-blown obsessive-compulsive disorder. If one takes this a step further, the

occurrence of obsessions and compulsions in individuals with no overt symptoms of OCD should also be mentioned.

1.4.1.5 “Normal” Obsessions and Compulsions

Most people at some time experience unpleasant intrusions similar in content to obsessions and compulsions in OCD but less intense and causing less discomfort (Muris, Merckelbach & Clavan, 1997). This supports the idea that symptoms of OCD form a continuum of severity; therefore it is possible for an individual to have obsessions and compulsions without this constituting a disorder or causing a great deal of distress. If repetitive activities and interests in ASD can be considered within the OCD model, they may be within the “normal” range.

1.4.1.6 Summary

This section has highlighted several key themes. Firstly, the idea that obsessions and compulsions are not restricted to people diagnosed with OCD - they are also apparent in compulsive hoarding; they may be a component of a particular personality “type”, and they occur in people with no overt clinical difficulties. As with ASD, obsessions and compulsions can therefore be said to form a spectrum. This implies that in order to determine that repetitive and restricted interests and activities are motivated in the same way as obsessions and compulsions, one would not necessarily be looking for evidence of a particular “disorder”. Rather, there might be various markers. The foregoing review has suggested what some of these might be, for example: interference with everyday social and occupational functioning,

resistance, anxiety/discomfort, an elevated sense of responsibility, indecisiveness, perfectionism, emotional attachment to objects, to name a few. The question remains: how applicable are these constructs to the behaviours in question? Having examined psychological models, the next stage is to consider evidence relating obsessions and compulsions to ASD.

1.4.1.6 Obsessions, Compulsions and Autistic Spectrum Disorders

As stated earlier, the terms "obsession" and "compulsion" are frequently mentioned in relation to ASD, and in relation to repetitive behaviours and narrow interests. So what is the evidence for a relationship?

Bolton, Pickles, Murphy & Rutter (1998) found OCD to be significantly more common in relatives of people with autism than those of people with Down's syndrome and that people with OCD were more likely to demonstrate social and communication difficulties akin to those manifested in autism. According to Hollander (1997), several studies have demonstrated that drugs used to treat OCD (serotonin reuptake inhibitors such as clomipramine and fluoxetine) can reduce repetitive behaviours in ASD. This suggests a link between the two disorders.

However, Ghaziuddin, Tsai & Ghaziuddin (1992) note that it can be difficult for people with ASD to report inner distress and feelings of compulsion, hence diagnosis of OCD is problematic. Baron-Cohen (1989b) argues that without this subjective evidence the behaviours of autistic individuals cannot be defined as either obsessions or compulsions. The link

can therefore be made on a behavioural level only. Baron-Cohen claims that these feelings would not be accessible to people with ASD owing to a ToM deficit. He even suggests that repetitive behaviours and interests might be ego-syntonic. However, the lack of evidence for Baron-Cohen's argument and the limited relevance of theory of mind to this area suggests that an explanation based on theories of OCD should not be disregarded just yet.

McDougle, Kresch, Goodman, Naylor, Volkmar, Cohen & Price (1995) have pointed out that inability to verbalise subjective states is not evidence of their absence. They conducted a case-controlled investigation of the *content* of (though not *motivation for*) the repetitive thoughts and behaviour of 50 people with ASD and 50 with OCD, using the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) symptom checklist (Goodman, Price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989), a clinician-rated inventory of 74 obsessions and compulsions. A relative or carer assisted.

The results indicated that most people in both groups reported repetitive thoughts and behaviour of multiple categories. Fifteen members of the ASD group were mute; of the remaining 35 only eight appeared to make active efforts to suppress their thoughts and to resist their repetitive behaviour. In the OCD group, 47 out of 50 participants experienced their obsessions and compulsions as excessive or unreasonable, and attempted to suppress the thoughts and resist the behaviour. There were significant differences between the two groups in terms of the type of thoughts and

behaviour reported; for example the ASD group were less likely to report aggressive and contamination obsessions and checking and cleaning compulsions, and more likely to report repetitive thoughts regarding need to know and behaviours involving ordering and hoarding.

The results of this study suggest that there are significant differences between the types of repetitive thoughts and behaviours experienced by people with ASD and those with OCD, though they are present for both groups. Again there is a lack of evidence for associated ego-dystonia in ASD, though some participants reported feelings of resistance. McDougle et al noted that the DSM IV criteria of recognition that the behaviour is excessive or unreasonable may be waived for children and suggested that people with learning disabilities should be treated similarly.

On the whole the evidence for a link between ASD and OCD is mixed, but there is certainly enough to warrant further investigation, in particular into the question of motivation for repetitive thoughts and behaviours. The OCD “hypothesis” remains a viable explanation for these features of ASD. However, there is an alternative, discussed in the following section.

1.4.2 Hobbies

So far, the proposed explanations for repetitive and restricted interests and activities in ASD have focused on deficits or problematic “symptoms”. However, the possibility remains that they are functional. In the general population there are many interests and activities that are engaged in

intensively and repetitively and are considered important and positive parts of life - hobbies. The final explanation for repetitive and restricted interests and activities in ASD to be considered here is that they may be comparable in terms of motivation to specialist hobbies (collecting, bird watching etc.).

There is little psychological literature available on this subject, and what there is seems to focus on the phenomenon of collecting. There has been debate regarding the distinction between collecting and hoarding. Belk (1995:67; cited in Belk, 1995, pp. 479) defines collecting as "the process of actively, selectively and passionately acquiring and possessing things removed from ordinary use and perceived as part of a set of non-identical objects or experiences". Belk further suggests that it is the lack of functional use and the uniqueness of each object that differentiates collecting from hoarding. Greenberg, Witzum & Levy (1990) suggest that in "normal" collecting (as opposed to compulsive hoarding), those involved are proud of their collections and enjoy displaying them. The time and space involved is said not to interfere with work, though it may be a substitute for more social activities. Conversely, hoarders are said to be ashamed of their possessions and the space they occupy.

There have been many proposals regarding the motivation for collecting. Early psychoanalytic thought related it to the sexual drive, particularly the "anal stage" of development, during which there was said to be a refusal to give and a desire to gather and hoard; or the aggressive drive, as a component of which collecting was said to resemble hunting (Formanek,

1991). More recent psychoanalytic theories have suggested that collecting represents the need of the individual to explore, be in contact with others and search for personal stability or psychological security (Formanek, 1991; Muensterberger, 1994, cited in Belk, 1995, pp. 479). Beaglehole (1932:310-311; cited in Olmsted, 1991, pp. 289) suggested that "the main value of a collection consists in the fact that it symbolises successful competition and before others the fact of success, power, gratified ambition and heightened self-esteem".

Olmsted (1987; cited in Olmsted, 1991, pp. 294) surveyed stamp collectors, who reported that their collections provided them with social interaction, pride, an activity to replace work, the opportunity to display their skills, and a source of support during life-problems. Formanek (1991) collected descriptive data from 167 collectors. There was evidence for multiple motivations, including maintenance of self-esteem; search for knowledge or mastery; defence against feeling low; a sense of belonging to an acceptable group of people; sharing and communicating with others; financial investment; and addiction, obsession or compulsion (though these latter categories lacked operational definitions).

Danet & Katriel (1989) presented data from semi-structured interviews with 85 adult and 80 child collectors. They suggested that important factors include sense of ownership, control and accomplishment. Their main hypothesis was that collectors strive for a sense of closure or perfection.

So far, the message is that collecting has positive functions for the individual concerned. Belk (1995) argues that collecting can also have negative consequences. For example, he suggests that a collection may become the person's only source of enjoyment; it may become a focus for excessive expenditure, resulting in shame and secrecy; and it may absorb time and affection that might otherwise be bestowed on other people. Wallendorf & Belk (1987; cited in Belk, 1995, pp. 483) found that many children and spouses of collectors viewed the collection as a rival.

Despite these drawbacks, it would seem that the body of opinion views collecting as an ego-syntonic process that serves the varying needs of the individual. There is some suggestion of an obsessional component, but this remains ill-defined and unsubstantiated. If one were to equate the repetitive and restricted interests and activities in ASD to hobbies such as collecting one would therefore, based on the preceding review, expect to find evidence of a positive function for the activity in terms of self, social activity or some other factor inherent in the particular behaviour. This is in contrast to the ego-dystonia attached to OCD, and the deficit-based models of ASD discussed earlier.

Having reviewed the relevant literature, the next section will condense it into a rationale for the current study.

1.5 Rationale for the Present Study

The preceding review has demonstrated that repetitive and restricted interests and activities are not adequately explained by theory or research related directly to ASD. These behaviours are often described as obsessional or compulsive. Whilst there is some evidence for a general link between ASD and OCD, the specific relevance to restricted and repetitive interests and activities is not clear.

It has been suggested that, owing to a “theory of mind” deficit, people with ASD are unable to report the subjective sense of ego-dystonia that is necessary for a diagnosis of OCD. However, there is evidence that the ToM deficit is not absolute (e.g. Bowler, 1992); throwing doubt on this assumption. Despite this, it seems that no-one has systematically attempted to find out.

If repetitive and restricted interests and activities are obsessional and/or compulsive, this has negative connotations for two main reasons. Firstly, the label implies interference in everyday social and occupational functioning; and secondly, OCD is defined as a psychiatric disorder, and as such is considered as something to be eliminated. There is evidence that some drugs are effective in reducing repetitive behaviours in ASD (Hollander, 1997), but without conclusive evidence that these behaviours are indeed problematic for the individual the question remains as to whether intervention is appropriate, desirable or indeed ethical. In order to determine this, it is argued here that one would need to know what the motivation is for these activities and interests - what function they serve for the individual, what, if

any, impact they have on social interaction and any meaningful occupation and, as a whole, whether these behaviours can be considered ego-dystonic or ego-syntonic.

As yet there have been no published attempts to answer this question. McDougle et al (1995) looked at *content* of repetitive thoughts and behaviour in ASD, but not motivation. They also looked exclusively at well-known types of obsession and compulsion, not the idiosyncratic interests and behaviours found in ASD. Some of their participants reported resistance and distress - further evidence that information regarding affect can be elicited.

The alternative to the OCD hypothesis is that restricted and repetitive interests and activities have a positive function and are ego-syntonic. We assume this to be the case for people in the general population who have specialist hobbies, and the existing research with collectors on the whole supports this conclusion.

This study therefore aims to explore the question of motivation for restricted and repetitive interests and activities in ASD - is it more akin to OCD or to a specialist hobby? If the former is the case one would expect reports of subjective distress or anxiety, an excessive sense of responsibility, interference with everyday life, and possibly the more general traits of indecisiveness or perfectionism. If the latter case is true, then one would expect the interest or activity to serve a purpose for the individual possibly related to self-esteem, social contact, or a sense of closure.

In order to conduct such a study, it has been decided to select those individuals with relatively intact language ability, to enable interviewing. Many of the participants may therefore have a diagnosis of Asperger's syndrome. Bearing in mind the earlier discussion of the difficulties involved with differential diagnosis, all are considered as functioning on some part of the autistic spectrum.

This study is based on theory and research related to OCD, since there is already some evidence of a link. Rather than testing a specific component of a specific model the aim is to identify key features. In the discussion section, an attempt will be made to link the findings with particular models within the OCD continuum, as well as theories of ASD and hobbies. The focus is on repetitive interests and activities reported by the participants, rather than "traditional" obsessions and compulsions as in McDougle et al's (1995) study. The opinion of a relative or carer will be sought as a comparison with the participants' own reports. As suggested by McDougle and colleagues, the criterion that any distress be recognised as excessive and/or unreasonable will be waived.

To summarise, this study aims to extend the research that has already been conducted into the link between OCD and ASD, and to take it in a new direction - namely to focus on motivation for restricted and repetitive interests and activities. The broad research questions are as follows:

1. Is it possible to elicit information regarding motivation from high functioning people with ASD?

2. Is there a motivational difference between high functioning people with ASD and people in the general population who have specialist interests/hobbies ("hobbyists")?
3. Do high functioning people with ASD demonstrate either ego-dystonia or ego-syntonia?
4. How do the results relate to existing theory and research regarding OCD?

1.6 Research Hypotheses

Based on the preceding rationale and research questions, the following main hypotheses will be investigated.

1.6.1 Hypothesis 1

H1: People with ASD will be able to give coherent accounts of their motivation for engaging in repetitive and restricted interests and activities.

H0: People with ASD will be unable to give coherent accounts of their motivation for engaging in repetitive and restricted interests and activities.

1.6.2 Hypothesis 2

H1: Hobbyists will be able to give coherent accounts of their motivation for engaging in these hobbies.

H0: Hobbyists will be unable to give coherent accounts of their motivation for engaging in these hobbies.

1.6.3 Hypothesis 3

H1: People with ASD will give ego-dystonic accounts of motivation (OCD hypothesis). Specifically in comparison with hobbyists, people in the ASD group will report:

- a) Significant interference in their everyday social or occupational functioning from thoughts or behaviour related to their interest or activity.
- b) Significant distress or discomfort associated with thoughts about their interest or activity and with behaviours related to it.
- c) A significant sense of compulsion related to their thoughts and behaviours associated with their interest or activity.
- d) Significant resistance to carrying out behaviours associated with their interest or activity.
- e) Significant avoidance associated with their interest or activity.
- f) An excessive sense of responsibility.
- g) Significant indecisiveness.

In addition:

- h) Over all, the ASD group will report motivations related to a need for harm-reduction.

H0: People with ASD will not give ego-dystonic accounts of motivation.

1.6.4 Hypothesis 4

H1: Hobbyists will give ego-syntonic accounts of motivation. Specifically, in comparison with the ASD group, hobbyists will report:

- a) Little interference in everyday social and/or occupational functioning from thoughts or behaviour related to their hobby.
- b) Little discomfort or distress associated with thoughts or behaviour related to their hobby.
- c) Little sense of compulsion related to their thoughts and behaviours associated with their hobby.
- d) Little resistance to carrying out behaviours associated with their hobby.
- e) Little avoidance associated with their hobby.
- f) No excessive sense of responsibility.
- g) Little indecisiveness.

In addition:

- h) Over all, hobbyists will report motivations related to some positive function(s) that their hobby serves for them associated with, for example, to self-image, social functioning, or finance.

H0: Hobbyists will not give ego-syntonic accounts of motivation.

1.6.5 Hypothesis 5

H1: Informants for both the ASD and hobbyist groups will agree with participants as to the nature of their motivations.

H0: Informants for either or both of the ASD and hobbyist groups will not agree with participants as to the nature of their motivations.

Section 2

Method

Section 2: Method

2.1 Design

This study was a between groups comparison (ASD or hobbyist). The main measure was a semi-structured interview.

2.2 Participants

Participants with ASD were either in contact with a local support group or were known to the CHASAC team, and had received a diagnosis of ASD. Participants were sought who were likely to be without learning disabilities which would preclude participation in an interview.

Members of the hobbyist group were recruited because they had an unusual or specialist interest, activity or collection that was an important part of their lives. They were contacted via museums, clubs/societies, and word of mouth.

All participants were over 18 years of age. Each person was asked if a close relative or carer would take part in the interview.

2.3 Measures

2.3.1 Intelligence Measures

Verbal intelligence was assessed using the British Picture Vocabulary Scale - Long Form (BPVS; Dunn, Dunn & Whetton, 1982). Reliability and validity of this measure has been established with people up to the age of 17 years, 11 months (Dunn et al, 1982). The aim of its use in the current study was to establish that participants had a reasonably adult vocabulary, hence it was deemed an appropriate measure.

Non-verbal intelligence was assessed using the Standard Progressive Matrices (SPM; Raven, 1976). Reliability and validity of this measure is well established for children and adults (Raven, Court & Raven, 1992).

2.3.2 ASD Screening Measures

2.3.2.1 Diagnostic Criteria

ASD is usually diagnosed during childhood via a lengthy interview (with child and parents/carers) and observation. Formal diagnostic screening was therefore beyond the scope of this study. Members of the ASD group had all received a diagnostic assessment at some point; members of the hobbyist group were established during the interview process to be functioning independently and to have no such diagnosis. Interviews were conducted

with awareness of DSM-IV diagnostic criteria and in no case were concerns raised.

2.3.2.2 Pragmatics Profile of Early Communication Skills

An adapted version of the Pragmatics Profile of Early Communication Skills (Dewart & Summers, 1988) was developed; for the purposes of the current study it was deemed that the questions incorporated in the profile would draw out the most prominent difficulties experienced by people with ASD, even in adulthood. Alterations were made to exclude any child-specific references, e.g. school. The revised measure was piloted on two relatives of hobbyists and one close friend of a person with ASD. It has 27 open-ended questions (Appendix 1), responses to which are not given a numerical value but are summarised by the clinician. There is no available reliability or validity data.

Since the Pragmatics Profile was to be used as a screening measure, it was decided to allocate each participant a score based on the number of responses to items which would warrant concern regarding that person's pragmatic ability (the minimum score was zero and the maximum 27). The aim was to establish a difference between the groups in terms of their pragmatic ability, thus lending weight to the diagnostic distinction between them. As such, each completed questionnaire was scored independently by the author and a second, blind, rater. Reliability data are given in the results section.

2.3.2.3 Interview Questions

Participants (and their informants) were asked about their social relationships (number of friends and how easy/difficult they found it to relate to other people) based on the assumption that individuals in the ASD group would report fewer friends and more difficulty in relating.

2.3.3 Measure of Obsessive-Compulsive Symptoms

The Obsessive-Compulsive Inventory (OCI) (Foa, Kozak, Salkovskis, Coles & Amir, 1998) was used to measure obsessive and compulsive symptoms. This is a 42-item self-report scale assessing washing, checking, doubting, ordering, obsessing, hoarding and mental neutralising (Appendix 2). It has been found to have good internal consistency and discriminative validity, and satisfactory convergent validity; as well as good test-re-test reliability (Foa et al, 1998). In Foa et al's (1998) study people with OCD obtained a mean score on the OCI of 66.33 (standard deviation, 31.9); the control group scored a mean of 25.25 (standard deviation, 20.8).

The OCI was originally devised to assess frequency and severity of symptoms separately. However, the correlations between these two factors are high (Foa et al, 1998) and it has been recommended that only the severity scale be used (Salkovskis, 1998, personal communication).

2.3.4 Semi-Structured Interview

The semi-structured interview used to assess motivation was based on the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) (Goodman, Price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989). This measure assesses key features of OCD and can be used as either an interview or a self-report measure (Steketee, Frost & Bogart, 1996).

The main part of the Y-BOCS is a 10-item, clinician rated scale, with separate sub-totals for severity of obsessions and compulsions. Assessment does not focus on content of symptoms but on how much they occupy the individual's time, interfere with normal functioning, cause subjective distress and can be controlled. The original scale also included a measure of resistance, but it was found that the scale performed better without this (Woody, Steketee & Chambless, 1995). There is an additional, investigational component in the form of questions that assess avoidance, indecisiveness, pathological responsibility, pathological slowness and doubting. Ratings on these items are not included in the total score because of a lack of evidence that they measure core features of OCD (Goodman, Price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989).

The Y-BOCS has good inter-rater reliability and internal consistency (Goodman, Price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989) and good convergent validity (Goodman, Price, Rasmussen, Mazure, Delgado, Heninger & Charney, 1989). The mean total score for

people with OCD is 21.8 (standard deviation, 8); the mean obsessions score is 10.7 (standard deviation, 4); and the mean compulsions score is 11.1 (standard deviation, 4) (Goodman, Price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989).

The main questions in the semi-structured interview were taken directly from the Y-BOCS. Unlike the former, however, definitions of obsessions and compulsions were not given at the beginning and terminology was altered so that there were references to interests/hobbies, thoughts and behaviours, rather than to obsessions and compulsions. The revised scale was piloted on two people with hobbies and one with ASD.

In addition to the Y-BOCS questions, the interview comprised questions to elicit further detail concerning motivation:

- “Why do you do it?”
- “What is the best thing about it?”
- “What is the worst thing about it?”

Each response was categorised by the author, initially yielding 31 categories. These were then grouped within 11 superordinate categories, as shown in Table 1, below. The subordinate categories therefore became in effect an operational definition for the superordinate categories.

Table 1: Response categories for the “why”, “best” and “worst” questions

Superordinate category	Subordinate categories	Example of response
Factor inherent in the hobby	Aesthetics	Beauty, attractiveness
	Flexibility/scope of interest	Can do it anywhere
	Uniqueness	Doing something different
	Environmental factors	Conservation
	Something concrete about the interest/activity	Uniforms, characters
	General appeal of the subject	Just a fascinating subject
	Activity levels required	Keeps me active
Social factors	Sharing with others	Others' interest in it
	Social events/activities	Socialising
	Meeting people	Meeting people
Factors related to self/relationships	Safety/security	Security
	Relationship substitute	Don't have to concentrate like I do with people
	Sense of achievement	Pleasing when you do well
	Sense of identity	My hobby is me
	Builds self esteem/confidence	I feel better about myself
	Perfectionism	I'm a bit of a perfectionist
	Fulfills a personal need	It “feeds” me
Emotional factors	Affect attached to activity	Excitement
	Escapism	I escape into that world
	Inspiration	Inspiration for my own work
	The “hunt” and/or discovery	The hunt and the kill
Skill/intellect	Puzzle/problem-solving	It's like a jigsaw puzzle
	Skill involved	Being a specialist
	Knowledge-acquisition	Adding to a store of knowledge
	Order/logic/rules	I like arranging and re-arranging them
	Competition	Friendly rivalry
	Challenge	It's a challenge
	Professional interest	I used to work in the field
	Family history	His father was a collector
Personal history	Something about own past	Finding my roots - I didn't know my own family
Possession	Of objects	I like to have them
Completion	For example, of sets	Completion
Obsessive or compulsive	Obsessive or compulsive factors	It can get a bit obsessive
Nothing	For example, no best or worst thing	There is no worst thing
Don't know	Don't know	I'm not sure

Once the initial categorisation was completed, responses were given to a second, blind rater who allocated them to superordinate categories. Inter-rater reliability was then calculated. Analysis was conducted on the basis of the number of people giving responses within each category.

Other questions were as follows:

- “How do you feel when you are engaged in your interest/activity?": coded as positive or negative.
- “Do you choose to do it, or do you have to?": “yes” or “no” depending on whether the participant reported choice.
- “After you have done it, do you feel better or worse about yourself?": coded as “better”, “worse” or “no different”.
- “Do you ever try to stop yourself from doing it?": “yes” or “no”.

For the above five questions the coding was straightforward, therefore reliability checks were not considered necessary.

The interview is in Appendix 3.

2.3.5 Questionnaire for Relatives

Relatives were asked to complete a self-report form of the interview (with the best/worst questions omitted) which asked for their view of their relative's interest/hobby. Again the revised questionnaire was piloted. As it was self-report, no inter-rater reliability was calculated, other than for questions that required categorization of responses.

2.4 Procedure

People with ASD and their families were contacted by a letter which explained the study and included a reply slip to be returned if they were interested in taking part (See Appendix 4).

Participants in the hobbyist group were also contacted by letter (See Appendix 4), most of which were sent via museum curators or club secretaries. The groups were not matched for age or gender, as it was felt that it would be too difficult to recruit enough people in this way.

People who returned the reply slip were contacted by telephone and given the opportunity to discuss the study in more detail and ask questions. A visit was then arranged.

Each participant was seen only once, sessions lasting between 1½ and 2½ hours. Time was taken at the beginning of the meeting for further discussion of the study with both participants and informants (where available) and to establish written informed consent. Meetings took place at the individual's home. Those people with ASD for whom no informant was available tended to be living independently, therefore were judged able to give consent themselves.

The BPVS, SPM and OCI^a were administered to the participant; following which the semi-structured interview was completed. All questions on the interview schedule were asked, further exploratory questions were added where necessary to clarify answers or to elicit other relevant information so that items could be rated by the interviewer. Informants (where present) completed their questionnaires at the same time. In most cases the informant went into a separate room; however in a few cases informants for the ASD group preferred to remain with their relative. For ethical purposes it was considered important to allow them this choice. Interviews were audiotaped in the majority of cases (one participant in the ASD group preferred this not to be done).

2.5 Ethical Approval

Proposals were submitted to the West Berkshire Local Research Ethics Committee and the Oxfordshire Psychiatric Research Ethics Committee in July 1998; ethical approval was granted in September 1998. The East Berkshire Local Research Ethics Committee granted approval in December 1998; based on the proposal already approved by the West Berkshire Committee.

See Appendix 5 for copies of letters confirming approval.

^aOwing to an administrative error, the version of the OCI used was incomplete. Efforts were made to rectify this by re-contacting participants by letter and asking them to fill in a second (complete) copy. The implications of this will be discussed further in the results and discussion sections.

In consultation with course staff it was decided that hobbyists who lived outside the above regions could be contacted. This decision was made on the basis that they were all adults, living independently, and not being approached via any health or community services but via organisations (museums and societies) that do not fall within any public service and therefore are not the responsibility of any regional ethical body. The fact that approval for the study as a whole had been granted by three ethics committees was considered sufficient to guarantee its ethical status.

Section 3

Results

Section 3: Results

Where parametric tests are used, normality of distribution has been established by Kolmogorov-Smirnov Goodness of Fit tests (Table in Appendix 6); where non-parametric tests are used data are not normally distributed or are categorical.

Where kappa coefficients are used to assess inter-rater reliability or participant-informant agreement, the following gradings are used (Landis & Koch, 1977):

<0=poor agreement

0-0.2=slight agreement

0.21-0.4=fair agreement

0.41-0.6=moderate agreement

0.61-0.8=substantial agreement

0.81-1.0=almost perfect agreement

In some cases kappa coefficients could not be calculated owing to gaps in the data set. In addition, kappa values can be somewhat distorted in cases where most agreements are loaded into one cell and there are minor disagreements elsewhere. This was often the case in the current data set. For these reasons, percentage agreement is also quoted. Seventy per cent and above is considered to represent good agreement (Lipinski & Nelson, 1974).

3.1 Sample Data

3.1.1 Response Rate and Sample Size

Response rates and sample sizes are presented in Table 2, below.

Table 2: Response rates and numbers interviewed

Group	Number of letters sent	Number who agreed to participate (% of letters sent)	Number interviewed (% of those interviewed)
ASD	50	16 (32%)	16 (100%)
Hobbyist	72	25 (34.72%)	21 (84%)
Total	122	41 (33.61%)	37 (90.24%)

One hundred and twenty two letters were sent to potential participants; affirmative responses were received from 41 people (33.61 per cent). All 16 people in the ASD group were interviewed. Twenty one hobbyists were interviewed - two were omitted because they could not be contacted and two because they responded after data collection was complete. The final sample therefore consisted of 37 people. Informant data was available for 12 of the ASD group (75 per cent) and 14 hobbyists (66.7 per cent).

3.1.2 Demographic Data

The male to female ratio was 3:1 (75:25 per cent) for the ASD group and 16:5 (76.2-23.8 per cent) for the hobbyist group.

Mean age and scores on the BPVS and Standard Progressive Matrices are given in Table 3, below.

Table 3: Age and scores on intelligence measures

Group	Age (in years)		BPVS ^a score (age in years)		SPM ^b Score	
	Mean	Std. Deviation	Mean	Std. Deviation	Mean (and grade ^c)	Std. Deviation
ASD	27.25	8.18	15.93	4.31	39.27 (V)	14.15
Hobbyist	54.67	12.11	19.25	0.87	47.10 (III)	7.08

^a British picture Vocabulary Scale; ^b Standard Progressive Matrices; ^c Grades are as follows:

- I: Superior
- II: Above average
- III: Average
- IV: Below Average
- V: Intellectually impaired

- **Age:** An independent samples t-test indicated that the hobbyists were significantly older than the ASD group ($t=7.79$; $d.f.=35$; $p<0.0005$, two-tailed).
- **Verbal IQ:** The BPVS scores were not normally distributed. The hobbyist group scored significantly higher (Mann-Whitney $U=75.5$; $z=-3.41$; $p=0.001$, two-tailed) than the ASD group.
- **Non-verbal IQ:** This was investigated using the SPM raw scores. A Levene's test indicated that equality of variances could not be assumed, therefore a Mann Whitney U-Test was used, demonstrating no significant difference between the two groups ($U=110.0$; $z=-1.526$; NS, two-tailed). However, the difference between the grades attached to the mean scores (III for the hobbyists and V for the ASD group) is clinically significant.
- **Pragmatic ability:** The Pragmatics Profile was only available for participants with an informant; 26 were completed. For reliability purposes, 22 (84.62 per cent) of these questionnaires were also scored by a blind rater. A Pearson correlation indicated good reliability ($r=.84$; $p<0.0005$, two-tailed). The ASD group had a mean score of 15.6 (SD=4.58); the hobbyist group had a mean score of 2.14 (SD=2.63). An independent

samples t-test indicated this difference to be significant ($t=-9.41$; $d.f.=24$; $p<0.0005$, two-tailed).

As an additional screening tool, two simple questions regarding number of friends and ease of relating to others were asked of both participant and informant. Table 4 shows the response categories for these questions and the frequencies within them (expressed as percentages, owing to the difference in sample size between the groups).

Table 4: Responses to questions about social relationships

Group	Number of friends: frequency of responses in each category (%)					Ease of relating to others: frequency of responses in each category (%)		
	None	Few, Not Close	Few, Close	Several, Not Close	Several, Close	Easy	Difficult	Mixed/variable
ASD ^a	56.3	31.3	6.3	6.3	0.0	12.5	43.8	37.5
ASD informant ^b	45.45	36.36	0.0	9.09	9.09	0.0	72.73	27.27
Hobbyist ^c	4.8	4.8	0.0	4.8	85.7	81.0	9.5	9.5
Hobbyist informant ^d	0.0	0.0	0.0	0.0	100.0	85.74	7.14	7.14

^a N= 16 ^b N=11, ^c N=21, ^d N=14

The “number of friends” question yielded small frequencies in some categories, therefore chi-square tests could not be performed to compare the groups. The data were re-coded into three categories: “none”, “not close” (“few, not close” and “several, not close” combined) and “close” (“few, close” and “several, close” combined). Despite this, a chi-square analysis was still not possible, as three of the cells had an expected count of less than five. Inspection of the data suggests that both hobbyists and their informants reported more and closer friendships than the ASD group and their informants. Good agreement between informants and participants across the

whole sample was indicated by a kappa coefficient of 0.86 (and 92 per cent agreement). Kappa coefficients could not be calculated for the ASD and hobbyist groups independently as some categories were empty. However, there was 81.9 per cent participant-informant agreement for the ASD group and 100 per cent agreement for the hobbyists.

For the “ease of relating” question, the data were re-coded into “easy” and “not easy” (“difficult” and “mixed/variable” combined). The ASD group reported significantly more difficulty in relating to other people than did the hobbyists (Fisher’s Exact Test, $p < 0.0005$). Substantial agreement between informants and participants was indicated by a kappa coefficient for the whole sample of 0.76. Agreement between hobbyists and their informants was moderate ($\text{kappa} = 0.42$); similarly for the ASD group ($\text{kappa} = 0.5$). Despite this, the percentage agreement was high: 88 per cent for the whole sample, 85.7 per cent for the ASD group and 90 per cent for the hobbyist group.

Obsessive and compulsive symptoms were measured using the OCI (Obsessive-Compulsive Inventory). As mentioned in the method section the initial questionnaire was incomplete (18 out of 42 items missing). Participants were re-contacted and asked to complete a full version; 30 were returned (12 For the ASD group and 18 for the hobbyist group). The remainder were pro-rated by calculating the mean score on the missing items for each group and adding the relevant figure to the participant’s original score. Table 5, below, shows the mean scores for each group.

Table 5: Scores on the Obsessive-Compulsive Inventory

Group	Mean	Standard Deviation
ASD	48.44	24.56
Hobbyist	11.16	9.17

An independent samples t-test indicated that the ASD group scored significantly higher than the hobbyist group ($t= -6.391$; $d.f.=34$; $p<0.0005$, two-tailed).

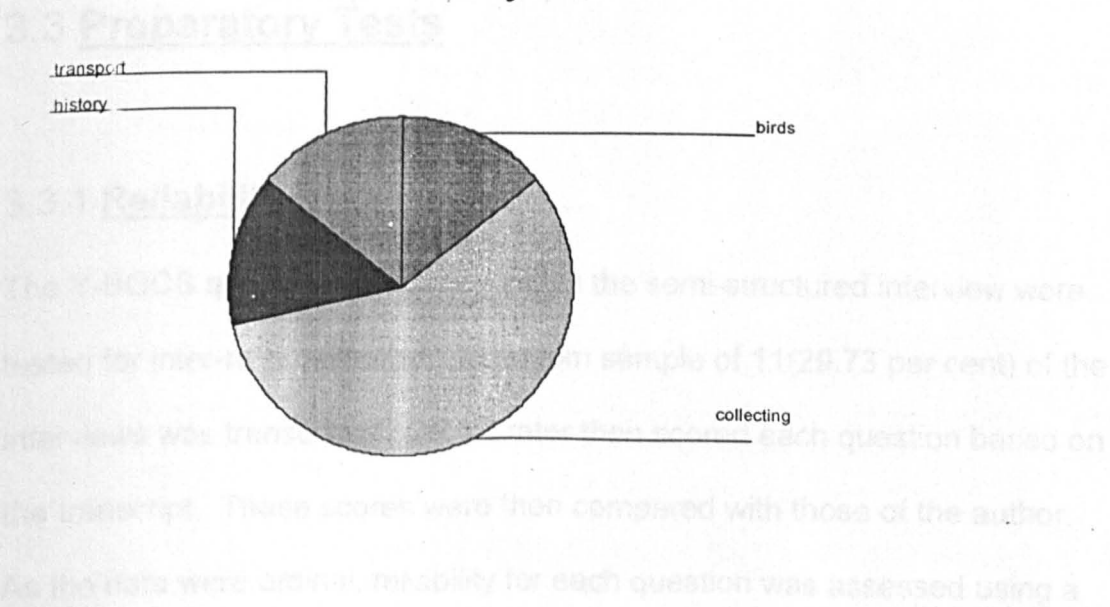
3.2 Descriptive Statistics

3.2.1 Nature of interests

The following pie charts (Figures 2.1 and 2.2) show the nature of participants' interests.

Figure 2.1: nature of interest

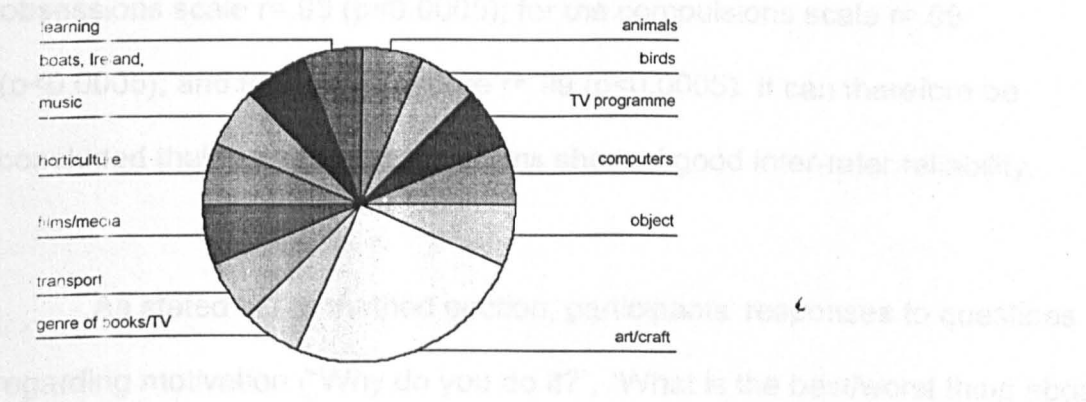
GROUP: Hobbyist



Most of the hobbyists interviewed were collectors (N=12; 57 per cent); other interests being birds (N=3; 14.3 per cent); history (N=3; 14.3 per cent); and transport (N=3; 14.3 per cent).

Figure 2.2: nature of interest

GROUP: Autistic spectrum disorder



Aside from the category of arts or crafts (N=4; 25 per cent), the ASD group were very idiosyncratic in their interests - each of the other categories was reported by one person only (6.3 per cent).

3.3 Preparatory Tests

3.3.1 Reliability

The Y-BOCS questions contained within the semi-structured interview were tested for inter-rater reliability. A random sample of 11(29.73 per cent) of the interviews was transcribed; a blind rater then scored each question based on the transcript. These scores were then compared with those of the author. As the data were ordinal, reliability for each question was assessed using a

non-parametric correlation, Kendall's tau_b. Most of the questions produced correlations of greater than .8, except for those regarding the interference of thoughts with work and control over drive, which scored .78 ($p=0.01$) and .74 ($p=0.01$) respectively. A full table of correlations can be seen in Appendix 7. The total Y-BOCS scores were normally distributed, therefore reliability was tested using Pearson's correlations. The results were as follows: for the obsessions scale $r=.93$ ($p<0.0005$); for the compulsions scale $r=.99$ ($p<0.0005$); and for the total score $r=.99$ ($p<0.0005$). It can therefore be concluded that the Y-BOCS questions showed good inter-rater reliability.

As stated in the method section, participants' responses to questions regarding motivation ("Why do you do it?", "What is the best/worst thing about it?") were categorised. Inter-rater reliability was assessed on the basis of responses from 35 participants (94.59 per cent) and 21 informants (80.77 per cent). The results are in Table 6, below.

Table 6: Inter-rater reliability for categories of motivation - participant and informant data.

Category	Participants		Informants	
	Kappa value	Percentage agreement	Kappa value	Percentage agreement
Inherent	0.5**	80.0%	0.63**	81.0%
Social	0.87***	94.3%	1.0***	100.0%
Self/relationships	0.55***	77.1%	1.0***	100.0%
Emotional	0.26	65.7%	0.88***	95.2%
Skill/intellect	0.5***	74.3%	0.55***	80.9%
Personal history	0.48***	94.3%	0.83***	95.3%
Possession	1.0***	100.0%	0.64**	95.3%
Completion	0.89***	97.2%	a	100.0%
Obsessive/compulsive	a	100.0%	1.0***	100.0%
Don't know	1.0***	100.0%	a	100.0%

^aNo responses fell within this category, therefore kappa was not calculated.

** $p<0.01$; *** $p<0.001$

As shown in the above table, for the “why” question, kappa values varied from 0.26 (fair agreement) to 1.0 (almost perfect agreement) for participants and from 0.55 (moderate agreement) to 1.0 for informants. Percentage agreement was over 70 per cent (and in most cases between 80 and 100 per cent) in all categories with the exception of the one labelled “emotional”. It can be concluded therefore that, with the exception of this one category, inter-rater reliability was acceptable.

For the “Best” and “Worst” questions, reliability was assessed in the same way, but for participants only, as informants were not asked this question. The scores are in Table 7, below.

Table 7: Inter-rater reliability for response categories in the “best” and “worst” questions.

Category	“Best thing”		“Worst thing”	
	kappa	Percentage agreement	kappa	Percentage agreement
Inherent	0.4*	71.5%	0.77***	88.6%
Social	1.0***	100.0%	0.65***	97.2%
Self/relationships	0.21	85.8%	a	97.1%
Emotional	0.38**	77.1%	1.0***	100.0%
Skill/intellect	0.79***	97.1%	a	97.1%
Personal history	b	100.0%	b	100%
Possession	a	94.3%	a	97.1%
Completion	b	100.0%	a	97.1%
Obsessive/compulsive	b	100.0%	0.65***	97.2%
Nothing	1.0***	100.0%	1.0***	100.0%
Don't know	1.0***	100.0%	1.0***	100.0%

^a One rater did not place any responses in this category, therefore kappa was not calculated by SPSS.

^b neither rater placed any responses in this category, therefore kappa was not calculated by SPSS.

*p<0.05; **p<0.01; ***p<0.001

Inter-rater reliability ranged from a kappa value of 0.21 (slight/fair agreement) to 1.0 (almost perfect agreement). Percentage agreement was over 70 per cent in all cases. It can therefore be concluded that reliability was satisfactory.

3.4 Investigation of Hypotheses

3.4.1 Methods of Analysis

Data were analysed using the SPSS-9 package. Because of the small sample size and the tendency of responses to cluster at one end of ordinal scales or in one category, it was often necessary to re-code the data into fewer categories to allow statistical analysis. Where this has been done, all subsequent analyses have been conducted on the re-coded data. Where participant and informant data are compared, the analysis includes only those participants for whom informants were available.

3.4.2 Hypotheses 1&2:

Hypothesis 1: ***People with ASD will be able to give coherent accounts of their motivation for engaging in repetitive and restricted interests and activities.***

Hypothesis 2: ***Hobbyists will be able to give coherent accounts of their motivation for engaging in these hobbies.***

All of the ASD group apart from one (15/16) were able to give at least one reason for their engagement in their interest or activity; the mean number given was 3.31 (range: 0-7). All of the hobbyists (21/21) were able to give at least one coherent reason; the mean number given was 4.71 (range: 1-9). An independent samples t-test indicated this difference to verging on significant ($t=1.98$; d.f.=35; $p=0.06$, two-tailed).

The number of reasons given was significantly positively correlated with scores on both the SPM (Pearson's $r=.42$; $p=0.01$) and BPVS (Kendall's $\tau_b=.37$; $p=0.01$). In other words, the higher the participant's verbal and non-verbal intellectual ability, the more reasons for pursuing their interest or activity they gave.

3.4.3 Hypotheses 3, 4 and 5:

These hypotheses were tested together. Each figure refers to responses to one of the interview questions. Data for the ASD group, the hobbyist group, ASD informants and hobbyist informants are depicted together.

Hypothesis 3: *People with ASD will give ego-dystonic accounts of motivation (OCD hypothesis).*

Hypothesis 4: *Hobbyists will give ego-syntonic accounts of motivation.*

Hypothesis 5: *Informants for both the ASD and hobbyist groups will agree with participants as to the nature of their motivations.*

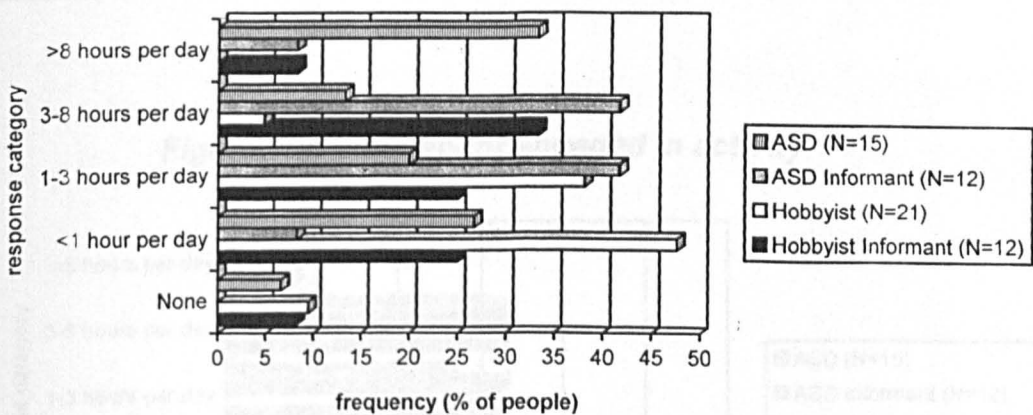
HYPOTHESES 3a AND 4a

Hypothesis 3 a): In comparison with the hobbyists, people in the ASD group will report significant interference in their everyday social or occupational functioning from thoughts or behaviour related to their interest or activity.

Hypothesis 4 a): In comparison with the ASD group, hobbyists will report little interference in everyday social and/or occupational functioning from thoughts or behaviour related to their hobby.

Amount of Time Spent Thinking About the Interest

Figure 3.1: Time spent thinking about interest/activity



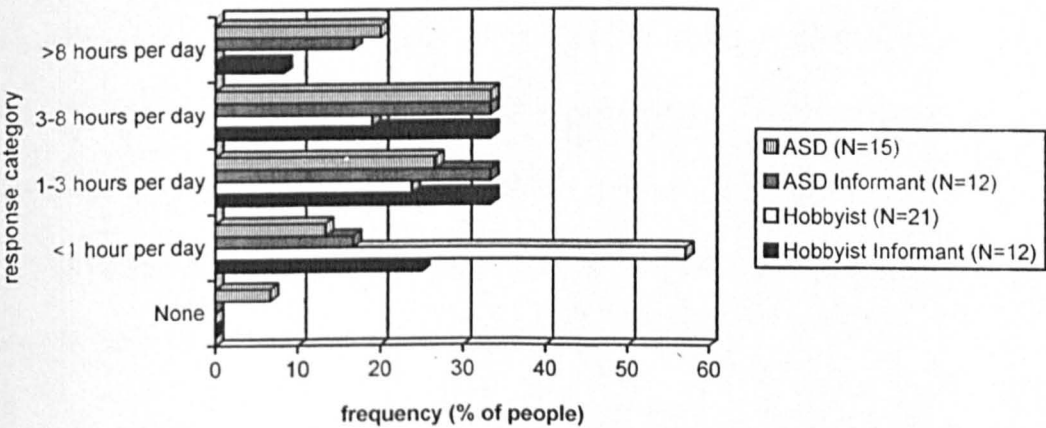
The median scores for this question were as follows: 2.0 for the ASD group; 2.5 for the ASD informants; 1.0 for the hobbyists; 2.0 for the hobbyist informants.

Response categories were re-coded into <1 hour, 1-3 hours and >3 hours. However, chi-square tests could not be performed as there were cells with an expected frequency of less than five. Inspection of the data suggests that the ASD group spend longer thinking about their interests than the hobbyists.

There was limited agreement between participants and informants: for the whole sample, kappa=0.19 (43.2 per cent agreement); for the ASD group kappa=0.35 (54.6 per cent agreement); for the hobbyists kappa=0.04 (33.3 per cent agreement). Inspection of the data suggests that informants for both groups reported slightly more time being spent thinking about interests than participants.

Amount of Time Spent Engaged In Behaviours Related to the Interest

Figure 3.2: Time spent engaged in activity



The median scores for this question were as follows: 3.0 for the ASD group;

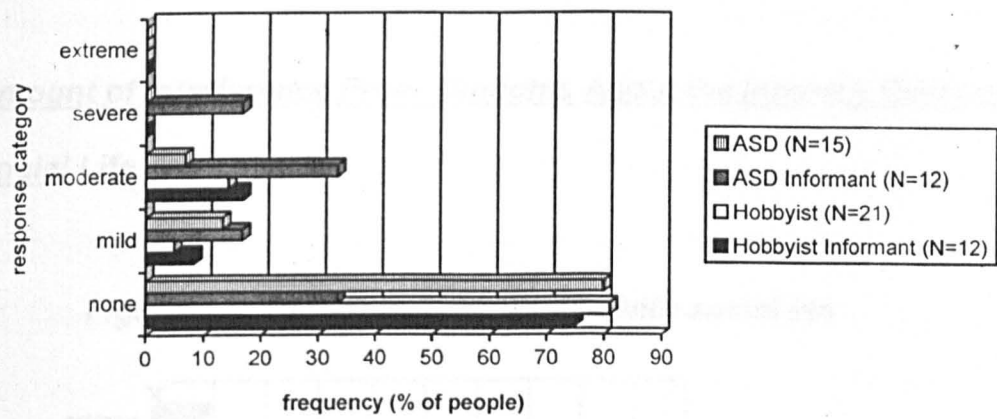
2.5 for the ASD informants; 1.0 for the hobbyists; 2.0 for the hobbyist informants.

Response categories were re-coded into <1 hour, 1-3 hours and >3 hours. However, chi-square tests could not be performed as there were cells with an expected frequency of less than five. Inspection of the data suggests that the ASD group spend more time than the hobbyists engaged in behaviours related to their interests.

There was limited agreement between participants and informants: for the whole sample, kappa=0.23 (47.8 per cent agreement); for the ASD group kappa=0.23 (54.6 per cent agreement); for the hobbyists kappa=0.18 (41.7 per cent agreement). Inspection of the data suggests that informants for the hobbyist group rated slightly more time being spent engaged in the hobby than participants.

Amount of Interference From Thoughts About the Interest: Effect on Work

Figure 3.3: Thoughts' interference with work



The median scores for this question were as follows: 0.0 for the ASD group; 1.5 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

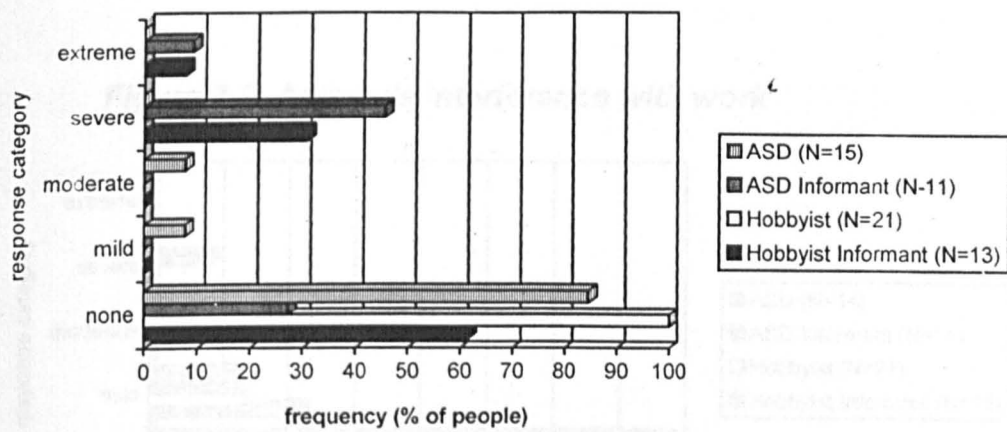
Response categories were re-coded into “none” and “some” (the latter being the “mild” - “extreme” categories merged). Both ASD and hobbyist participants reported their thoughts about their interests to be the source of very little interference in their work (be that paid employment, studying or household chores) - there was no significant difference between the two groups (Fisher’s Exact Test, NS); this was also the case according to informant data (Fisher’s Exact Test, NS).

According to kappa values, agreement between participants and informants was poor for the whole sample (kappa=-0.14) and for the ASD group (kappa=-0.39); for the hobbyists there was slight agreement

(kappa=0.18). Percentage agreement scores indicated a little more concurrence (47.8, 54.6 and 75 per cent respectively). Inspection of the data suggests that informants for the ASD group reported more interference than participants.

Amount of Interference From Thoughts About the Interest: Effect on Social Life

Figure 3.4: Thoughts' interference with social life



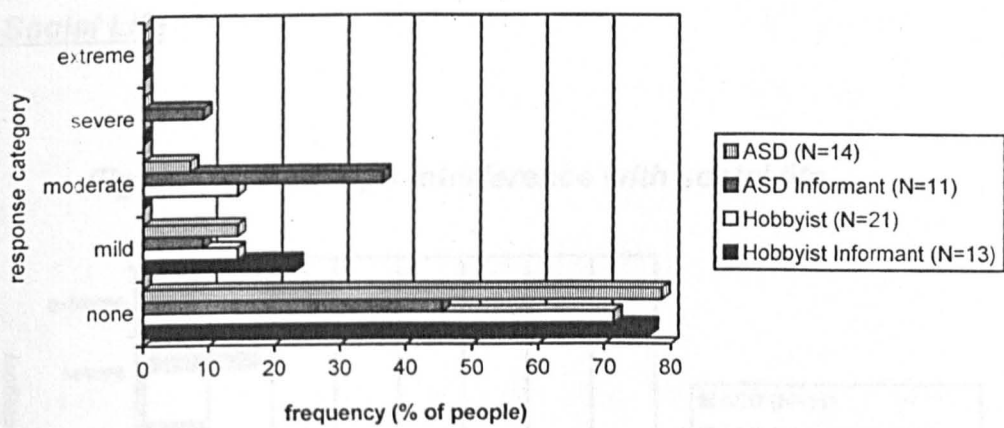
The median scores for this question were as follows: 0.0 for the ASD group; 2.0 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

Response categories were re-coded into "none" and "some". Both ASD and hobbyist participants reported their thoughts about their interests to cause little interference in their social life - there was no significant difference between the two groups (Fisher's Exact Test, NS); this was also the case according to informant data (Fisher's Exact Test, NS).

There was some agreement between participants and informants for the whole sample ($\kappa=0.08$, 52.1 per cent agreement) and for the ASD group ($\kappa=0.09$, 40.0 per cent agreement); for the hobbyists κ could not be calculated, but there was 61.5 per cent agreement. Inspection of the data suggests that informants for both groups reported more interference than participants.

Amount of Interference From Behaviours Related to the Interest: Effect on Work

Figure 3.5: Activity's interference with work^c



The median scores for this question were as follows: 0.0 for the ASD group; 1.0 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

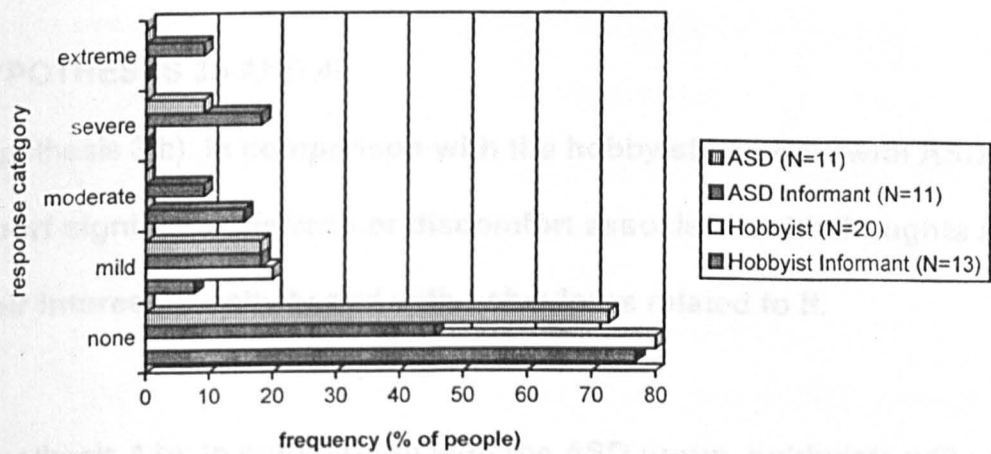
Response categories were re-coded into "none" and "some". Both ASD and hobbyist participants reported the activities associated with their interests to cause little interference in their work - there was no significant

difference between the two groups (Fisher's Exact Test, NS); this was also the case according to informant data (Fisher's Exact Test, NS).

According to kappa values, agreement between participants and informants was poor for the whole sample ($\text{kappa}=-0.16$), the ASD group ($\text{kappa}=0.0$) and the hobbyists ($\text{kappa}=-0.3$). Percentage agreement scores of 52.1, 50 and 53.8 per cent respectively suggest a little more concurrence. Inspection of the data suggests that ASD informants reported slightly more interference than participants.

Amount of Interference From Behaviours Related to the Interest: Effect on Social Life

Figure 3.6: Activity's interference with social life



The median scores for this question were as follows: 0.0 for the ASD group; 1.0 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

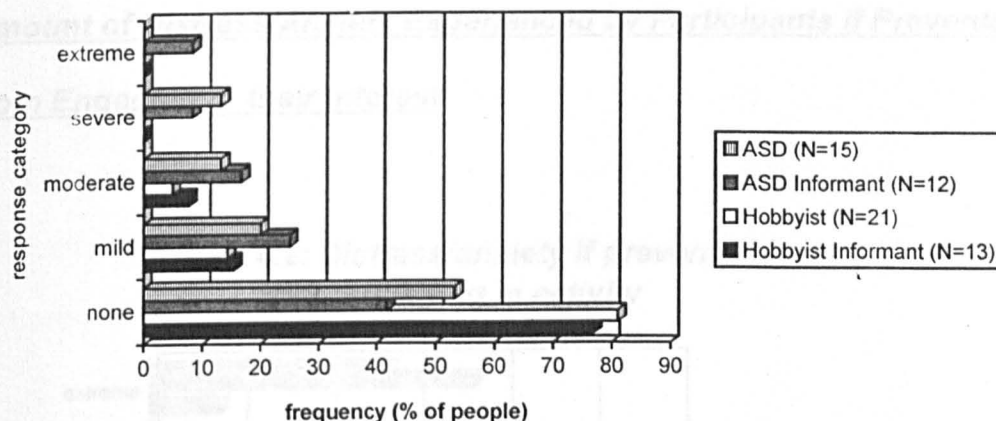
Response categories were re-coded into “none” and “some”. Both groups reported the activities associated with their interests to cause little interference in their social life - there was no significant difference between the two groups (Fisher's Exact Test, NS); this was also the case according to informant data (Fisher's Exact Test, NS).

According to kappa values, there was slight agreement between participants and informants for the whole sample ($\kappa=0.08$); fair agreement for the hobbyists ($\kappa=0.26$); but poor agreement for the ASD group ($\kappa=-0.25$). Percentage agreement scores suggested more concurrence for the full sample and the hobbyist group (61.9 and 76.9 per cent respectively), but agreement remained low for the ASD group (37.5 per cent agreement). Inspection of the data suggests that ASD informants reported slightly more interference than participants.

HYPOTHESES 3b AND 4b

Hypothesis 3 b): In comparison with the hobbyists, people with ASD will report significant distress or discomfort associated with thoughts about their interest or activity and with behaviours related to it.

Hypothesis 4 b): In comparison with the ASD group, hobbyists will report little discomfort or distress associated with thoughts or behaviour related to their hobby.

Amount of Distress Associated with Thoughts About the Interest**Figure 4.1: Distress associated with thoughts about interest**

The median scores for this question were as follows: 0.0 for the ASD group; 1.0 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

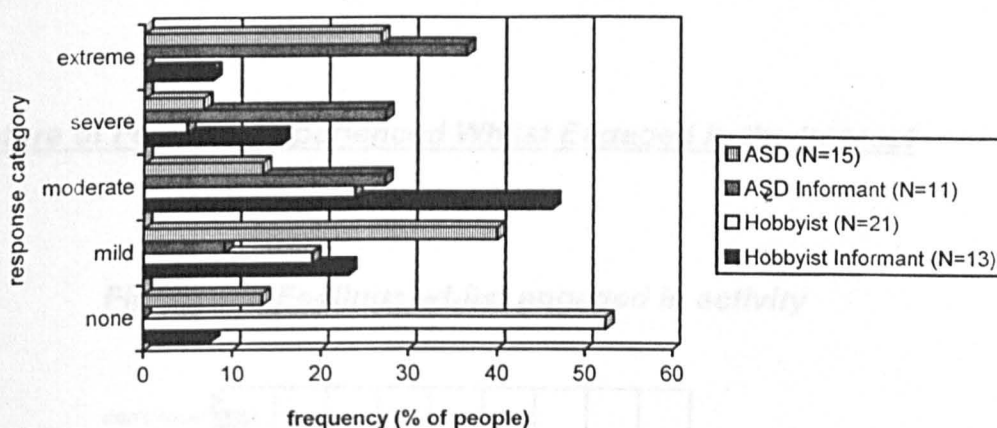
Response categories were re-coded into "none" and "some". Both groups reported the thoughts about their interests to be the source of little distress - there was no significant difference between the two groups (Fisher's Exact Test, NS); this was also the case according to informant data (Fisher's Exact Test, NS).

There was some agreement between participants and informants for the whole sample ($\kappa=0.19$, 62.5 per cent agreement) and the ASD group ($\kappa=0.07$, 54.6 per cent agreement). For the hobbyists, agreement was poor with a kappa value of -0.13 but percentage agreement was reasonable at 69.2 per cent. Inspection of the data suggests that ASD informants

reported participants to experience more distress than the latter did themselves.

Amount of Distress/Anxiety Experienced by Participants if Prevented from Engaging in their Interest

Figure 4.2: Distress/anxiety if prevented from engaging in activity



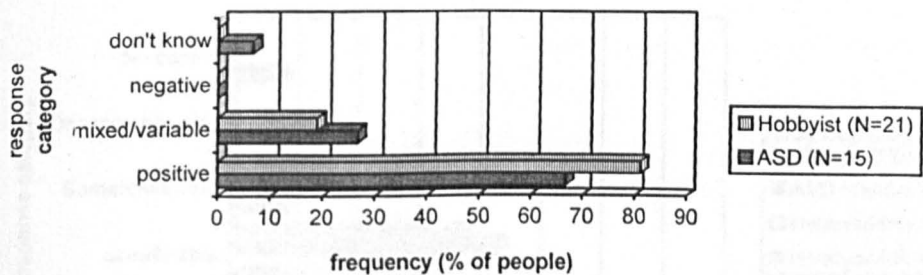
The median scores for this question were as follows: 1.0 for the ASD group; 3.0 for the ASD informants; 0.0 for the hobbyists; 2.0 for the hobbyist informants.

Response categories were re-coded into "none" and "some". The ASD group reported significantly more distress/anxiety if prevented from engaging in their interest/activity than the hobbyist group (Fisher's Exact Test, $p=0.03$); however according to informant data, there was no significant difference between the groups (Fisher's Exact Test, NS).

Agreement between participants and informants was poor for the whole sample and the hobbyists on the basis of kappa values of -0.08 and -0.16 respectively. Percentage agreement was 60.9 per cent for the whole sample and 38.5 per cent for the hobbyists. A kappa value was not calculated for the ASD group, but 90 per cent agreement suggests high concurrence between informants and participants. Inspection of the data suggests that hobbyist informants reported participants as experiencing more distress than they did themselves.

Nature of Feelings Experienced Whilst Engaged in the Interest

Figure 4.3: Feelings whilst engaged in activity



Response categories were re-coded into “positive” and “not entirely positive” (the latter consisting of the other three categories). Both ASD and hobbyist participants reported mostly positive feelings associated with their interest or activity - there was no significant difference between the two groups (Fisher’s Exact Test, NS).

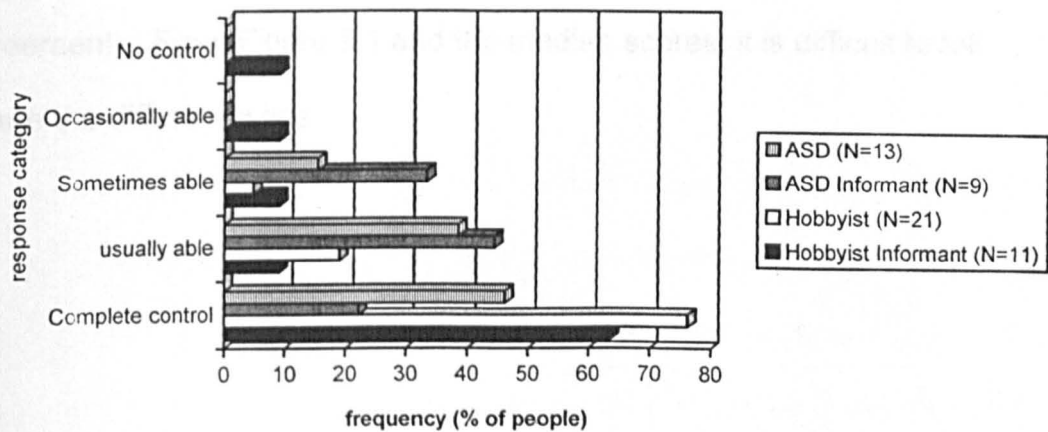
HYPOTHESES 3c AND 4c

Hypothesis 3 c): In comparison with the hobbyists, people with ASD will report a significant sense of compulsion related to their thoughts and behaviours associated with their interest or activity.

Hypothesis 4 c): In comparison in the ASD group, hobbyists will report little sense of compulsion related to their thoughts and behaviours associated with their hobby.

Amount of Control Over Thoughts About the Interest

Figure 5.1: Control over thoughts



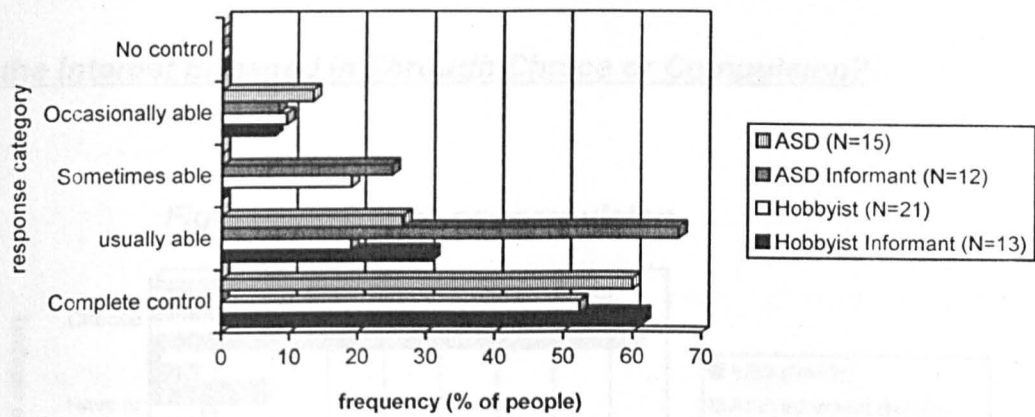
The median scores for this question were as follows: 1.0 for the ASD group; 1.0 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

The response categories were re-coded into "complete control" and "some control" (the latter consisting of the "usually", "sometimes" and "occasionally" categories, with the "no control" category being excluded). Both ASD and hobbyist participants reported a reasonable amount of control over their thoughts about their interests - there was no significant difference between the two groups (Fisher's Exact Test, NS); however, informants reported the ASD group to be significantly less able to control their thoughts about their interests than the hobbyists (Fisher's Exact Test, $p=0.002$).

Agreement between participants and informants was poor according to kappa values and limited according to percentage agreement for the whole sample (kappa=-0.03; 47.4 per cent agreement), the ASD group (kappa=0.0; 50 per cent agreement) and the hobbyists (kappa=-0.32; 45.5 per cent agreement). From Figure 5.1 and the median scores, it is difficult to tell where the difference lies.

Amount of Control Over the Drive to Engage in Behaviours Related to the Interest

Figure 5.2: Control over drive



The median scores for this question were as follows: 0.0 for the ASD group; 1.0 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

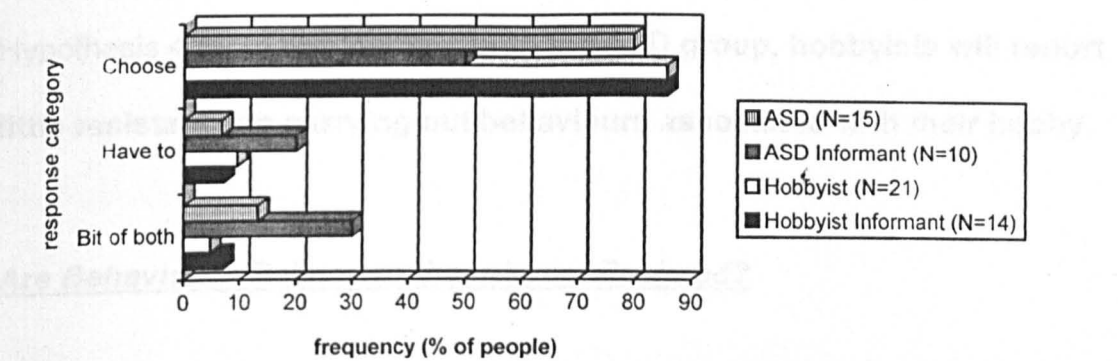
Response categories were re-coded into “complete control” and “some control”. Both ASD and hobbyist participants reported a reasonable amount of control over their drive to perform behaviours related to their interests - there was no significant difference between the two groups (Fisher’s Exact Test, NS); however, informants reported the ASD group to have significantly less control than the hobbyists (Fisher’s Exact Test, $p=0.002$).

There was some agreement between participants and informants for the whole sample ($\kappa=0.11$; 54.1 per cent agreement) and the hobbyists ($\kappa=0.22$; 61.6 per cent agreement). A kappa value was not calculated for

the ASD group, but 45.5 per cent agreement suggests only limited concurrence between informants and participants. Inspection of the data suggests that informants for the ASD group rated control lower than did participants.

Is the Interest Engaged in Through Choice or Compulsion?

Figure 5.3: Choice or compulsion



Response categories were re-coded into “choice” and “not entirely choice” (the latter consisting of the other two categories). Both groups clearly reported that they engage in their activities out of choice - there was no significant difference between the two groups (Fisher’s Exact Test, NS); this was also the case according to informant data (Fisher’s Exact Test, NS).

According to kappa values, there was reasonable agreement between informants and participants for the whole sample ($\kappa=0.31$) and for the ASD group ($\kappa=0.57$); for the hobbyist group it was poor ($\kappa=-0.09$). However, the percentage agreement was high (83.4 per cent for the whole sample and the ASD group, 83.3 per cent for the hobbyists). Inspection of

the data suggests that informants were slightly more likely to report a sense of compulsion than participants.

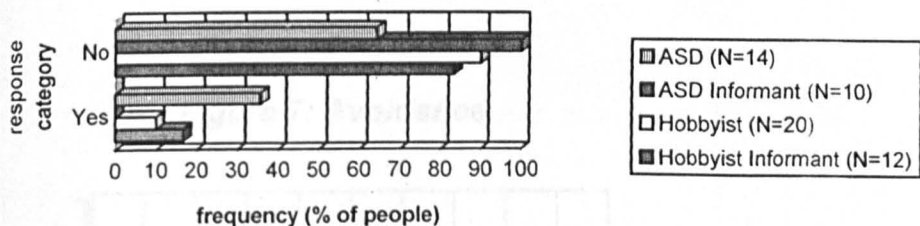
HYPOTHESES 3d AND 4d

Hypothesis 3 d): In comparison with the hobbyists, people with ASD will report significant resistance to carrying out behaviours associated with their interest or activity.

Hypothesis 4 d): In comparison with the ASD group, hobbyists will report little resistance to carrying out behaviours associated with their hobby.

Are Behaviours Related to the Interest Resisted?

Figure 6: Resistance to activity



Both ASD and hobbyist participants reported little resistance to their activities - there was no significant difference between the two groups (Fisher's Exact Test, NS); this was also the case according to informant data (Fisher's Exact Test, NS).

According to kappa values, agreement between informants and participants was poor for the whole sample ($\kappa=-0.16$) and for the

hobbyists ($\kappa=-0.16$); however there was 68.4 per cent and 72.7 per cent agreement respectively. Kappa was not calculated for the ASD group, but there was 62.5 per cent agreement. This suggests that there may have been more concurrence than suggested by the kappa values.

(Fisher's Exact Test = 0.02)

HYPOTHESES 3e AND 4e

Hypothesis 3e): **In comparison with the hobbyists, people with ASD will report significant avoidance associated with their interest or activity.**

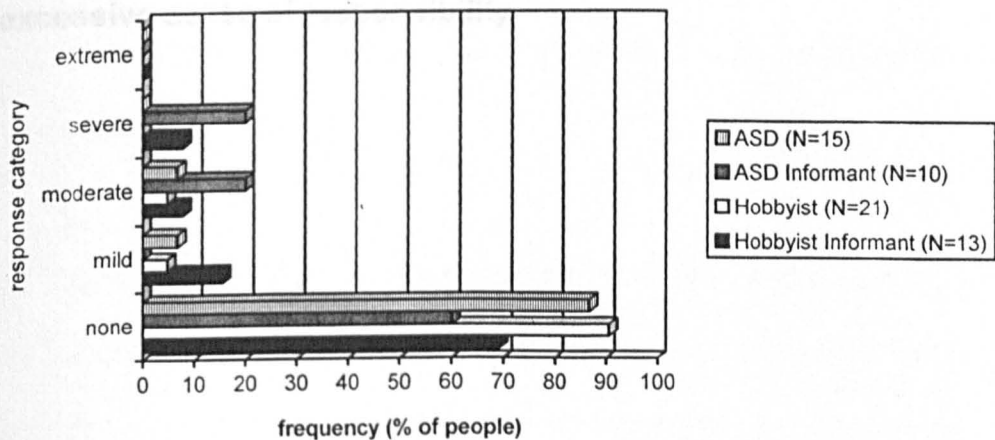
and the hobbyists response was 68.4 per cent, 72.7 per cent and 51.2

Hypothesis 4e): **In comparison with the ASD group, hobbyists will report little avoidance associated with their hobby.**

HYPOTHESES 3e AND 4e

Amount of Avoidance Owing to Thoughts or Behaviour Associated with the Interest

Figure 7: Avoidance



The median scores for this question were as follows: 0.0 for the ASD group; 0.0 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

Response categories were re-coded into "none" and "some". Both ASD and hobbyist informants reported very little avoidance associated with their interests - there was no significant difference between the two groups (Fisher's Exact Test, NS); this was also the case according to informant data (Fisher's Exact Test, NS).

Kappa values of -0.09, 0.09 and -0.26 suggest poor agreement between participants and informants for the whole sample, the ASD group and the hobbyists respectively. However, 56.5 per cent, 60 per cent and 53.8 per cent agreement (respectively) suggests slightly more concurrence.

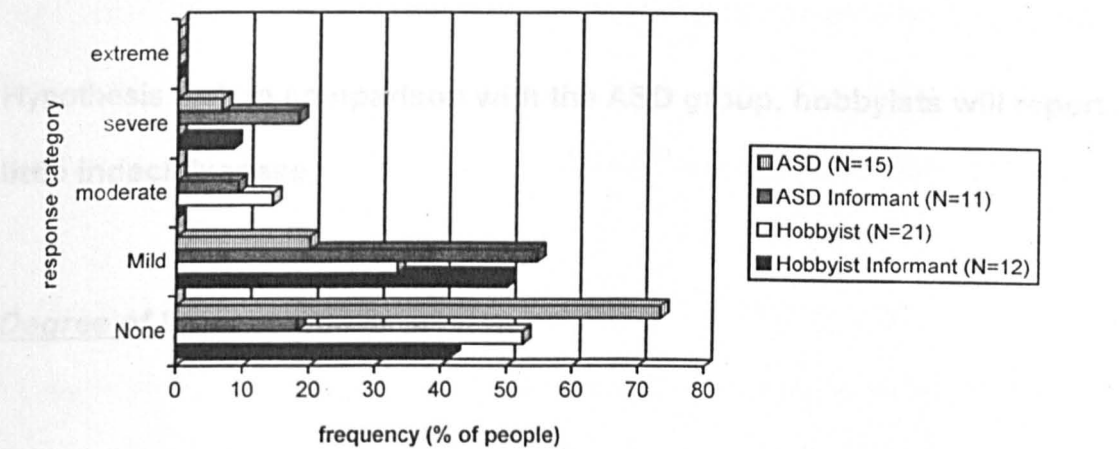
HYPOTHESES 3f AND 4f

Hypothesis 3f): In comparison with the hobbyists, people with ASD will report an excessive sense of responsibility.

Hypothesis 4f): In comparison with the ASD group, hobbyists will report no excessive sense of responsibility.

Degree of any Excessive Sense of Responsibility

Figure 8: Excessive sense of responsibility



The median scores for this question were as follows: 0.0 for the ASD group; 1.0 for the ASD informants; 0.0 for the hobbyists; 1.0 for the hobbyist informants.

Response categories were re-coded into “none” and “some”. Both ASD and hobbyist participants reported very little in terms of excessive responsibility - there was no significant difference between the two groups (Fisher’s Exact Test, NS); this was also the case according to informant data (Fisher’s Exact Test, NS).

Agreement between participants and informants was poor for the whole sample ($\kappa=-0.01$; 40.9 per cent agreement) and slight for the ASD group ($\kappa=0.05$; 30 per cent agreement) and the hobbyists ($\kappa=0.03$; 50 per cent agreement). Inspection of the data suggests that informants in both groups rated sense of responsibility slightly higher than participants.

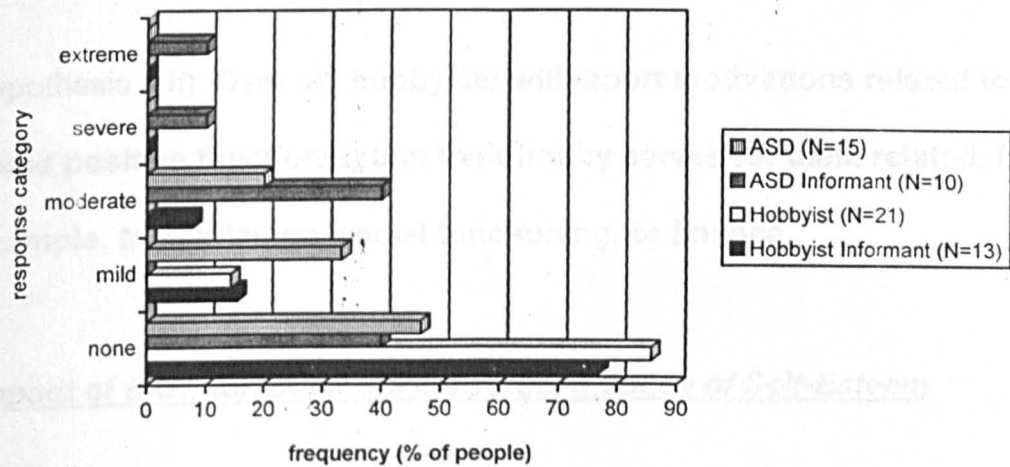
HYPOTHESES 3g AND 4g

Hypothesis 3 g): In comparison with the hobbyists, people with ASD will report significant indecisiveness.

Hypothesis 4 g): In comparison with the ASD group, hobbyists will report little indecisiveness.

Degree of Indecisiveness

Figure 9: Indecisiveness



The median scores for this question were as follows: 1.0 for the ASD group; 2.0 for the ASD informants; 0.0 for the hobbyists; 0.0 for the hobbyist informants.

Response categories were re-coded into “none” and “some”. The ASD group reported significantly more indecisiveness than the hobbyists (Fisher’s Exact Test, $p=0.03$); however according to informant data, there was no significant difference between the groups (Fisher’s Exact Test, NS).

Kappa values of -0.38, -0.35 and -0.13 suggest poor agreement between participants and informants for the whole sample, the ASD group and the hobbyists respectively. However, agreement of 54.6 per cent, 33 per cent and 69.2 per cent (respectively) suggests slightly more concurrence for the whole sample and the hobbyists. Inspection of the data suggests that ASD informants reported slightly more indecisiveness than participants.

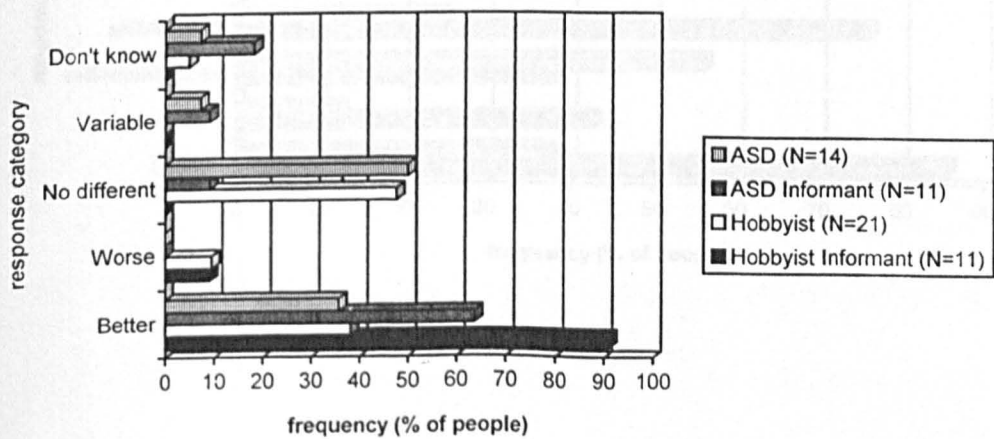
HYPOTHESES 3h AND 4h

Hypothesis 3 h): Over all, the ASD group will report motivations related to a need for harm-reduction.

Hypothesis 4 h): Over all, hobbyists will report motivations related to some positive function(s) that their hobby serves for them related, for example, to self-image, social functioning, or finance.

Impact of the Interest on the Individual's Sense of Self-Esteem

Figure 10.1: Impact on self-esteem



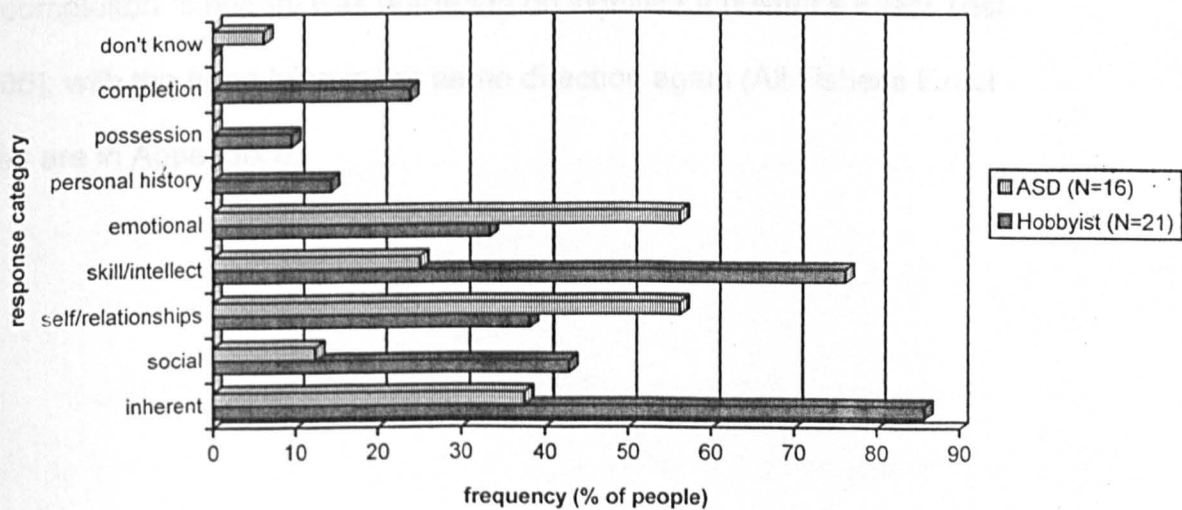
Response categories were re-coded into “better”, “worse” and “no different”, with the “variable” and “don’t know” responses being excluded. Chi-square tests could not be performed, as some cells had an expected frequency of less than five. Inspection of the data suggests that both the ASD and hobbyist groups tended to report that their interests make them feel either better about themselves or no different, rather than worse.

Agreement between informants and participants for the whole sample and the hobbyists was poor, as indicated by kappa coefficients of 0.01 (37.6 per cent agreement) and -0.09 (27.3 per cent agreement) respectively.

Agreement for the ASD group was fair (kappa=0.29; 60 per cent agreement).

Why Do You Engage in this Interest? Participants' Responses

Figure 10.2 Motivations



Inspection of the above chart suggests that the ASD group were most likely to

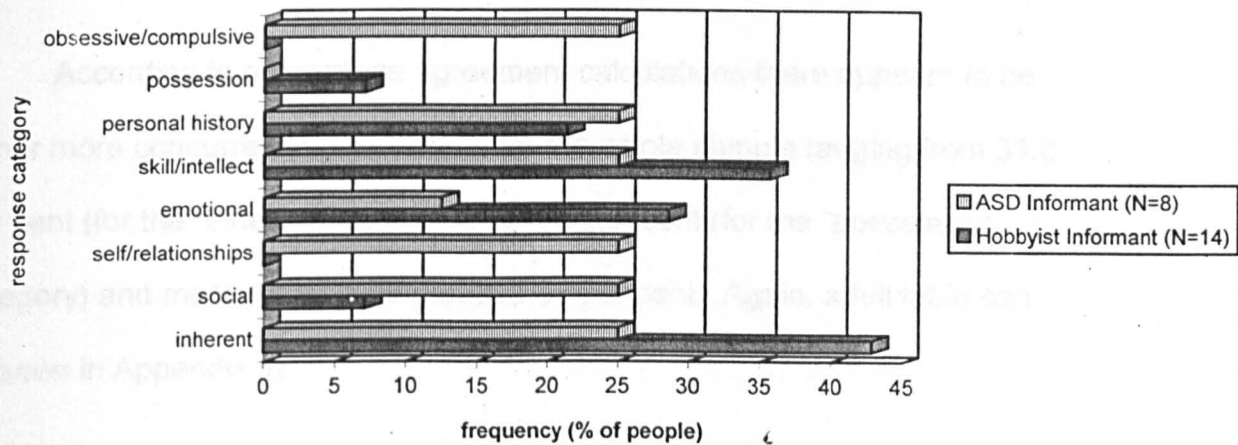
give responses indicating their motivators to be emotional or related to the self image and/or relationships. Hobbyists seem most likely to cite key motivators as being related to skill and/or intellect or a factor inherent in the hobby itself. Unfortunately, the author is not aware of a way to perform a statistical analysis of which categories each group was most likely to lean towards. It is clear, however, that participants' responses all reflected some positive function of the interest/activity or a positive feature of it - there were no participants who reported themselves to be motivated by a need for harm-reduction.

In most categories there was no significant difference between the two groups. The exceptions were as follows: the "inherent" category (Fisher's Exact Test, $p=0.01$; hobbyists cited these reasons more frequently); and the "skill/intellect" category (Fisher's Exact Test, $p=0.003$; again hobbyists cited these reasons more frequently). The difference between the two groups in the "completion" category was bordering on significant (Fisher's Exact Test, $p=0.06$), with the trend lying in the same direction again (All Fisher's Exact scores are in Appendix 8).

Why Does Your Relative Engage in this Interest? Informants'

Responses

Figure 10.3: Informant's opinion of motivation



Inspection of the above chart suggests that there was a lot of variance in the responses or informants for the ASD group. Informants for the hobbyists seem most likely to cite key motivators as being related to factors inherent in the hobby itself. Again it is clear that responses did not reflect a need for harm-reduction.

In no category was there a significant difference between the two groups (Fisher's Exact Tests in Appendix 8).

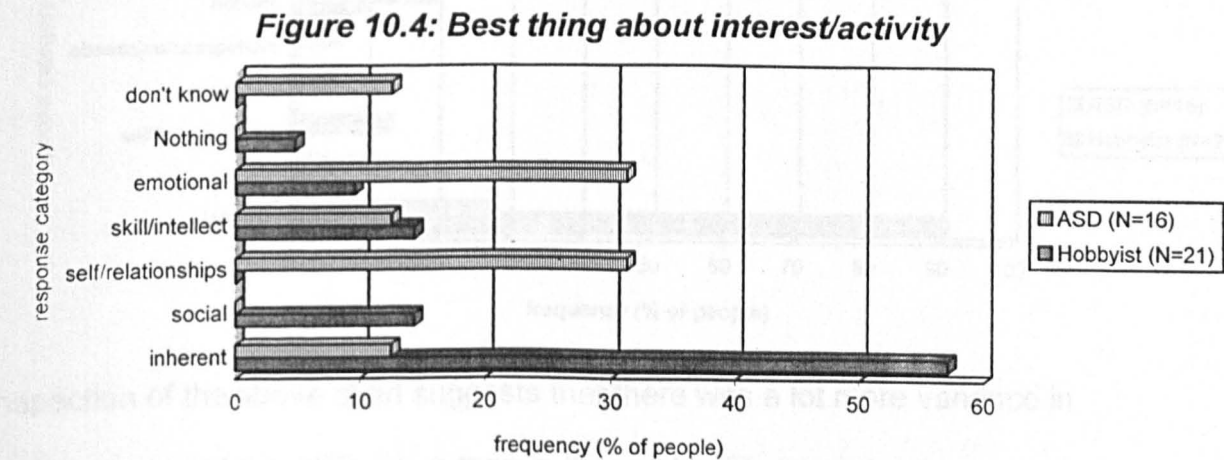
Agreement between participants and informants (as assessed with kappa coefficients) ranged from poor to substantial for the whole sample and for both the ASD and hobbyist groups independently. Most agreement was found in the "possession" category, in which there was complete agreement between informants and participants for the whole sample and for the

hobbyist group ($\kappa=1.0$; $p<0.0005$ in both analyses); and the “emotional” category, in which there was substantial participant-informant agreement for the hobbyist group ($\kappa=0.65$; $p=0.02$). A full table of kappa scores can be seen in Appendix 9.

According to percentage agreement calculations there appears to be rather more concurrence, with values for the whole sample ranging from 31.8 per cent (for the “inherent” category) to 100 per cent (for the “possession” category) and most values falling above 68 per cent. Again, a full table can be seen in Appendix 9).

The most reasonable conclusion is that agreement between participants and informants was variable.

The Best Thing About the Interest



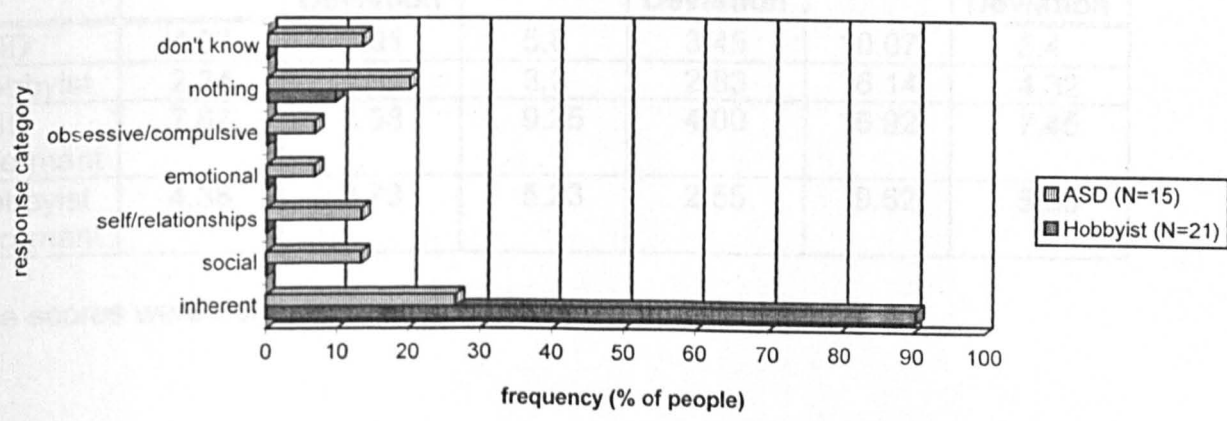
Inspection of the above chart suggests that the ASD group were most likely to report the “best thing” about their interest/activity as being related to an

emotional factor or to it's effect on some aspect of themselves or their relationships. Hobbyists seem most likely to cite key motivators as being related to factors inherent in the hobby itself. Again it is clear that responses did not reflect a need for harm-reduction or a strong compulsive element.

In most categories there was no significant difference between the two groups. The exceptions were as follows: the "inherent" category (Fisher's Exact Test, $p=0.02$), which responses of the hobbyists were more likely to fall into and the "self/relationships" category (Fisher's Exact Test, $p=0.02$), into which responses of the ASD group were more likely to fall. All Fisher's Exact scores are in Appendix 8.

The Worst Thing About the Interest

Figure 10.5: Worst thing about interest/activity



Inspection of the above chart suggests that there was a lot more variance in the responses of the ASD group than in those of hobbyists, who were most likely to report the "worst thing" about their interest/activity as being related to

factors inherent in the hobby itself. Again it is clear that responses did not reflect a need for harm-reduction.

In most categories there was no significant difference between the two groups. The only exception was the “inherent” category (Fisher’s Exact Test, $p<0.0005$), which responses of the hobbyists were more likely to fall into. All Fisher’s Exact scores are in Appendix 8.

Scores on the Y-BOCS

Table 8, below, gives details of participants’ scores on the obsessions and compulsions subscales of the Y-BOCS; together with the total score.

Table 8: Scores on the Y-BOCS

Group	Obsessions subscale		Compulsions subscale		Total score	
	Mean	Std. Deviation	Mean	Std. Deviation	Mean	Std. Deviation
ASD	4.27	2.91	5.8	3.45	10.07	5.4
Hobbyist	2.24	1.97	3.9	2.83	6.14	4.32
ASD Informant	7.67	3.98	9.25	4.00	16.92	7.45
Hobbyist Informant	4.38	3.73	5.23	2.55	9.62	5.55

The scores were normally distributed within each of the four groups.

The mean scores for people with OCD are as follows: total score=21.8 (SD=8); obsessions subscale=10.7 (SD=4); compulsions subscale=11.1 (SD=4) (Goodman, price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989). The scores given by ASD informants for each of the scales

are therefore approaching clinical significance (i.e. are within one standard deviation of the mean score for people with OCD).

The differences between the ASD and hobbyist groups were assessed using independent samples t-tests. There were significant differences for the obsessions subscale ($t=-2.5$; $d.f.=34$; $p=0.02$, two-tailed) and the total score ($t=-2.42$; $d.f.=34$; $p=0.02$, two-tailed), with the ASD group scoring higher on both. They also scored higher on the compulsions subscale, though this time the difference fell short of significance ($t=-1.81$; $d.f.=34$; NS, two-tailed).

Agreement between participants and informants was assessed using Pearson's correlations. For the ASD group the correlations were poor for the total score ($r=.01$; $p=0.98$) the obsessions scale ($r=-.04$; NS) and the compulsions scale ($r=.05$; NS). The same was true of the hobbyists group for the total score ($r=.22$; NS), obsessions scale ($r=-.17$; $p=0.62$) and compulsions scale ($r=.41$; NS). Inspection of the data suggests the informants' ratings to be higher than the participants' in each case.

3.5 Qualitative data

There are several observations, based on interviews, that may add to the information already described in this section:

- Members of the ASD group were able to distinguish obsessional and compulsive problems from their interests - eight members of this group described obsessions or compulsions as distinct from their interests.
- Often, members of the ASD group were quiet and seemed nervous at the beginning and end of interviews, but were highly animated and communicative when talking about their interests.
- Nearly all of the individuals in the ASD group were aware of their social difficulties and referred to them during interview.
- Though this is not clear from the data reported in this section, the way in which people with ASD spoke about their interests had a different feel to the way the hobbyists spoke. The ASD group seemed more emotional about it, and their interests seemed to have more of a role in their ability to function, or cope with life, than did those of the hobbyists. For example, if one looks at responses to the question "Why do you do it?"; those coded within the "self/relationships" category for the hobbyists were often related to achievement, perfectionism or a general sense of fulfilment; only one person referred to "proving [their] worth", and one described their hobby as a "substitute wife". By contrast, the responses of the ASD group often had clear references to self-esteem, for example: "Builds my confidence", "proving to myself that I can do something", "makes me feel like a good man", "feel better about myself". There were also references to the

difficulties of social relationships: "Easier to talk to than a person", "Don't have to concentrate like I do with people", "More predictable than people", "Have to make myself knowledgeable to get friends". These kinds of responses were not given by the hobbyists, nor were those referring to interests as helping the person to function: people in the ASD group made comments such as: "Sometimes I take on the role of a character when I'm out", "Helps me to get through life's problems", "I imagine taking him to work and sorting out the people who are unkind to me", "My hobby is me, I'm not sure I would have another outlet". The point is that although the categorised and quantified data did not seem to reveal large differences in motivation between the two groups, there seem to be more subtle, qualitative ones.

Section 4

Discussion

Section 4: Discussion

4.1 Overview

The aim of this study was to explore the motivation underlying restricted and repetitive interests and activities in autistic spectrum disorders (ASD). The main hypotheses were based on the idea of a relationship between ASD and obsessive-compulsive disorder (OCD); hence differences between ASD and hobbyist groups were sought in terms of key features of obsessive and compulsive symptomatology. These were: interference in occupational or social functioning; distress associated with thoughts and/or behaviour; a sense of compulsion; resistance; avoidance; an excessive sense of responsibility; and indecisiveness. It was expected that the interests and activities found in ASD would be ego-dystonic; and in contrast that those of hobbyists would be ego-syntonic and would have some positive function. In addition to self-report, the opinion of a relative or carer was sought; it was expected that informant data would support participant data.

This discussion will first summarise the findings of the study and will then address methodological issues arising from it. Interpretations of the results will be offered (including theoretical implications) and implications for clinical practice and future research considered, before final conclusions are drawn.

4.2 Summary of Research Findings

4.2.1 Demographic and Descriptive Data

There were significant differences between the hobbyist and ASD groups in terms of age and verbal intelligence. There was no statistical difference in terms of non-verbal intelligence, but there was a clinically significant difference. As expected, members of the ASD group and their informants reported fewer close relationships and more difficulty relating to other people than did hobbyists and their informants. The ASD group also scored significantly higher on the OCI than the hobbyist group. The ASD group had a greater range of interests and activities.

4.2.2 Reliability

The Y-BOCS questions used in the semi-structured interview showed good inter-rater reliability. The reliability of categories used to score responses to other questions, namely: "Why do you (does she or he) do it?", "What is the best thing about your interest?", "What is the worst thing about your interest?" was variable, but on the whole satisfactory. Kappa coefficients tended to suggest lower reliability than did percentage agreement calculations - this may be a result of the data often being clustered in one category. The actual reliability status of this coding system remains uncertain, therefore results reported on the basis of it should be interpreted with caution.

4.2.3 Ability to Give Coherent Accounts of Motivation

As expected, all participants (apart from one in the ASD group) were able to give at least one reason for engaging in their particular interest. The number of reasons given was significantly correlated with scores on the BPVS and SPM - i.e. the higher the participants' verbal and non-verbal intelligence, the more reasons they gave.

4.2.4 Nature of Motivation

4.2.4.1 Group Differences Based on Self-Report

Contrary to the initial hypotheses, no significant differences were found in:

- Interference
- Distress associated with thoughts about the interest/activity
- Feelings whilst engaged in the activity
- Sense of compulsion
- Resistance
- Avoidance
- Sense of responsibility.

Participants reported little interference or distress, positive feelings whilst engaged in the activity, a reasonable amount of control over their thoughts and behaviours, and little resistance, avoidance, or excessive responsibility.

There were a few differences between the groups. The ASD group reported significantly more distress or anxiety associated with prevention of their engagement in their interest/activity than did the hobbyist group; they also

reported significantly more indecisiveness. Inspection of the data suggested that the ASD group spend more time thinking about or engaged in behaviours related to their interests than the hobbyists.

In terms of the types of motivations reported, both groups seemed more likely to report feeling better about themselves or no different, as opposed to worse, following engagement in their interest. In response to the question about why they do these things, inspection of the data suggested that the ASD group tended to offer most endorsement to emotional factors, as well as those associated with self/identity or relationships; whilst hobbyists tended to offer most endorsement to factors related to skill or intellect, or to something inherent within the hobby. However, the majority of response categories yielded no significant difference between the hobbyist and ASD groups; the exceptions being the "inherent" and "skill/intellect" categories, which were both more likely to be endorsed by the hobbyist group.

When asked to describe the best thing about their interest/activity, most categories again yielded no significant group difference, the exceptions being the "self/relationships" category (significantly more likely to be endorsed by members of the ASD group) and the "inherent" category (significantly more likely to be endorsed by hobbyists). When asked to describe the worst thing about their interest, the only significant group difference was in the "inherent" category, with hobbyists more likely to endorse this. One person in the ASD group reported the worst thing to be a tendency for the interest to become "a bit obsessional at times".

The ASD group scored significantly higher on the total Y-BOCS score and the obsessions sub-scale; they also scored higher on the compulsions sub-scale but this result fell just short of statistical significance. Scores did not reach a level of clinical significance.

To summarise, contrary to the initial hypotheses, the accounts of motivation offered by the ASD group did not reflect ego-dystonia or a need for harm reduction. Instead, both groups reported motivational factors that suggest their activities and interests have positive functions for them - this was as predicted for the hobbyist group.

4.2.4.2 Group Differences Based on Informant Report

As predicted, informant data also yielded no significant differences between the ASD and hobbyist groups in terms of interference; distress associated with thoughts about the interest; compulsion; resistance, avoidance; or excessive responsibility. However, in contrast with participants, informants reported no significant differences between the ASD and hobbyist groups in terms of level of distress if prevented from engaging in the interest or activity, or indecisiveness. Also, according to informants the ASD group had significantly less control than the hobbyist group.

Agreement between informants and participants in both the ASD and hobbyist groups was assessed using kappa coefficients and percentage agreement calculations. The kappa values suggested low levels of agreement, the percentages somewhat more. The precise level of agreement between

participants and informants is unclear, but it does seem that the informants had a somewhat different view to the participants. Inspection of the data suggested that informants for both groups rated interference, compulsion and excessive responsibility as slightly more of a problem than participants did; ASD informants rated distress associated with thoughts and indecisiveness higher than participants did; and hobbyist informants rated distress/anxiety if prevented from engaging in the interest higher than participants did.

Similarly to participants, informants seemed to indicate the interests to increase self-esteem rather than reduce it. In terms of responses to the "why" question there were no significant differences between the ASD and hobbyist groups in any category. Two ASD informants (25%) cited obsessional or compulsive factors. Agreement between participants and informants was variable, and tended to be rather low.

In terms of the Y-BOCS data, informants too gave significantly higher scores for the ASD group than the hobbyist group. On the whole, informants gave higher scores than participants. The total score for the ASD group verged on clinical significance.

4.3 Methodological Considerations

There are various methodological factors to be considered when interpreting the results of this study.

4.3.1 Design

Conducting the study as a between-groups comparison meant the loss of individual differences within the groups. For example, though the data as a whole suggested that the interests and activities of the ASD group were not ego-dystonic, there were some individuals for whom this might have been less clear cut - a more qualitative, individualised approach may have revealed a spectrum incorporating varying degrees of ego-syntonia and ego-dytania.

4.3.2 The Sample

The sample was essentially self-selecting, calling into question its representativeness. The hobbyist group was dominated by collectors, almost certainly owing to the recruitment method of contacting museums, clubs and societies - these people were the most accessible. It is possible that findings would have been different had this group consisted of people who are more isolated in their pursuit of a specialist hobby; but recruitment would be difficult. For the ASD group people with adequate verbal skills were deliberately sought out. The question of how well the findings apply to less able people with ASD will be discussed further in due course.

The sample size was relatively small, making it difficult to analyse and interpret the data produced. Able adults with ASD are difficult to access as they tend not to be recipients of active input from health or social services. It was easier to recruit hobbyists, though the time taken to access them, their geographical diversity and the lengthy nature of the interviews placed limitations on the eventual size of the group.

The two groups were not matched for age, gender or IQ as it was felt that recruitment of a reasonable sample size would not be possible with this approach. As it turned out the gender ratios were almost exactly the same for both groups, but there were significant differences in terms of age and intelligence. Age was probably not a major issue, but verbal and non-verbal intelligence was correlated with the number of reasons that people were able to give for their interests, and may have impacted on the findings in more subtle ways not identified here.

A final issue regarding the sample size was the limited number of informants available. This meant that, not only were there individuals for whom pragmatics profile screening information was not available, but the informant data were difficult to analyse and interpret.

4.3.3 Measures

Finding an appropriate and simple measure for ASD was difficult. The Pragmatics Profile only examines one aspect of ASD, it has no reliability or validity data and was designed for use with young children. The questions that were asked about social relationships were derived from clinical experience rather than previous research. These two measures did discriminate well between the groups, but in future research one might want to systematise the screening process.

Although the Y-BOCS has good reliability and validity for people with OCD, there is a question about its utility with either "normal" populations or people with

ASD who have strong interests. Of particular concern with this measure are the questions about avoidance, responsibility, doubt and indecisiveness. As discussed in the methods section, these are more tentative in terms of their relationship to core features of OCD, therefore the findings based on them need to be interpreted with care. A further point about the Y-BOCS is that each factor is assessed by only one or two items - it may have been more valid to focus on fewer areas and conduct a more detailed assessment of each.

The informant questionnaire asked people to rate the thoughts as well as behaviour of their relatives - a difficult task. Although most informants managed to answer these questions, it is perhaps not surprising that agreement was often low.

The final point to be made regarding measures addresses the process of categorising responses to the "why", "best" and "worst" questions. These categories were largely arbitrary, created on the basis of participants' responses to the questions and, perhaps unsurprisingly, they showed variable inter-rater reliability. It may have been beneficial to undertake a more rigorous process of category formation, using several raters to develop them, however this would have been difficult within the scope of this study.

4.3.4 Procedure

As mentioned in the method section, there was a problem with the OCI - owing to an administrative error an incomplete version was used during interviews. Efforts were made to rectify this by re-contacting participants, however this situation was

clearly far from ideal. Although it would have been better in terms of the research to have all information collected at one point in time, none of the participants were receiving treatment for an identified obsessive-compulsive disorder, therefore one would not expect significant changes in their scores within the few weeks that elapsed between the interview and completion of a second questionnaire.

4.3.5 Data Analysis

Owing to the small sample size and the categorical nature of the data, analysis was limited in power. In some cases it was necessary to recode items to allow statistical analysis, and ordinal scales of five points frequently became dichotomous categories. If the sample size had been larger, or responses more varied (they tended to cluster at one end of the ordinal scales), analysis may have been feasible without having to code the data into fewer categories. As it was, it was decided to pursue statistical analysis rather than maintain the sensitivity of the scales.

In those cases where informant and participant data were compared, the sample size was reduced even further by including only those participants for whom an informant was available.

4.4 Interpretation of Research Findings

4.4.1 Obsessions and Compulsions

All but one of the ASD group were able to give coherent accounts of their interests and motivations, and in fact most of them were surprisingly eloquent about it this despite their often "below average" scores on tests of verbal and non-verbal intellectual ability. This throws doubt on the viewpoint that people with ASD cannot access or express their subjective inner experiences (Baron-Cohen, 1989b). In turn, the implication is that an explanation for repetitive and restricted interests and activities based on a model of OCD cannot be rejected on the basis of the ToM hypothesis.

The main hypotheses of this study suggested that motivations for repetitive and restricted interests and activities in ASD would differ from those of hobbyists and would reflect core features of obsessional and compulsive symptomatology. According to DSM-IV diagnostic criteria and the cognitive-behavioural model of OCD (Salkovskis, 1998) core features of OCD include interference in occupational and social functioning; distress associated with thoughts; a sense of compulsion/lack of control; avoidance; an excessive sense of responsibility; and resistance. Failure to find group differences and the fact that the scores of the ASD group did not reach clinical levels suggests that the OCD model is not a good fit. However, there was some evidence that the ASD group may be spending more time engaged in thoughts and activities related to their interests than the hobbyist group; and the ASD group also reported more

distress if prevented from pursuing their interests. So, what are the possible explanations for these findings?

- It may be that repetitive and restricted interests and activities in ASD bear no relation to obsessions and compulsions.
- It may be that members of the ASD group did not give an accurate report of their feelings and thoughts. However, this possibility does not fit with the impression gained by the interviewer.
- It may be that the measures used were not sensitive enough to pick up an obsessive or compulsive element; after all the Y-BOCS was designed for ongoing evaluation of symptoms in people with a pre-existing diagnosis of OCD, not for diagnosis (Goodman, Price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989). In addition, each of the factors listed above was assessed by only one or two items in the interview; perhaps there would have been more significant results with a more detailed measure, or indeed a larger sample size.
- It may be that, although a model of full-blown OCD does not fit, there are more subtle elements to be unpacked. This possibility will be considered next.

Despite the lack of significant differences on individual items, the total Y-BOCS scores and scores on the obsessions sub-scale were significantly higher in the ASD group than the hobbyist group; scores on the compulsions sub-scale were also higher, though this difference fell just short of significance. This may have been an artifact, but inspection of median scores throughout does suggest a slight tendency for ASD participants to make higher ratings than hobbyists. It

may be that these more global scores are emphasising real differences that are too subtle to be picked up by analysis of individual items, particularly within such a small sample. So perhaps the ASD group are just a little bit further along the OCD continuum than the hobbyists when it comes to their restricted interests; though still falling short of clinical significance.

Data from the open questions yielded no suggestion of a need for harm-reduction or ego-dystonia; in fact both groups reported positive feelings about their interests and a beneficial (or no) effect on their self-esteem. Only one person in the ASD group mentioned a tendency for their interest to be "a bit obsessive at times". Two ASD informants suggested some sort of compulsive element to the interests. This, together with the higher Y-BOCS scores in the ASD group suggests that perhaps there is a slight obsessional or compulsive element to these interests in ASD, but without any associated ego-dystonia. This would be more in line with Frost & Gross' (1993) examination of compulsive hoarding - they too found little evidence of ego-dystonia, though there were problems associated with the behaviour, particularly in terms of conflict with family members. Though there was no evidence of family conflict in the current study, informants for both the hobbyists and ASD group did seem to regard the interests as interfering more with life than did participants. The emotional attachment (particularly for security) and indecisiveness described by Frost et al (1995) and Frost & Hartl (1996) was also more evident in the ASD group than the hobbyists. So, there may be some similarities between restricted and repetitive interests and activities in ASD and the presentation of compulsive hoarders. This

also fits with McDougle et al's (1995) finding that hoarding behaviour was more commonly reported in ASD than OCD.

The motivations described by participants and informants indicate that Baron-Cohen (1989b) may have been right when he suggested that repetitive and restricted interests and activities in ASD are ego-syntonic. In this respect there was little difference between them and hobbyists. However, as discussed above, there seems to be a slightly more obsessional or compulsive element than is found in hobbyists. A further relevant finding is that a large number of the ASD group did report obsessive or compulsive difficulties (their OCI scores were significantly higher than those of the hobbyists). This may lend weight to the suggestion of a link between OCD and ASD (Bolton et al, 1998), but it does not seem accurate to apply the OCD model strongly to restricted and repetitive interests and activities, particularly as the individuals concerned were able to distinguish their obsessions and compulsions from their interests.

In the introduction to this study it was suggested that obsessions and compulsions may be associated with particular personality traits or, in their milder forms, be "normal" occurrences. In terms of the former possibility, there was some evidence of increased indecisiveness in the ASD group, but personality factors were not investigated in detail. It also remains possible that any tendency towards obsessive or compulsive features in ASD is within "normal" parameters. This would be backed up by the lack of significant differences between the two groups on Y-BOCS items.

The links with the literature on obsessive and compulsive symptomatology have been explored; now this discussion will move on to look at the literature on hobbies.

4.4.2 Hobbies

The lack of substantial difference between the hobbyist and ASD groups suggests a link between the two in terms of motivation. There were certainly mentions of factors such as competition and success (suggested by Beaglehole, 1932; cited in Olmstead, 1991, pp. 289); search for knowledge or mastery and maintenance of self-esteem (Formanek, 1991); and perfectionism (Danet & Katriel, 1989) by both groups. The main tenet of the collecting literature, that hobbies have positive functions, seems to be supported by the findings of this study for both the ASD and hobbyist groups. However, there is also some suggestion that Belk's (1995) account of negative consequences of collecting may be of relevance, for example relatives of both hobbyists and people with ASD seemed to view these specialist interests or hobbies as somewhat problematic, particularly with regard to levels of interference with occupational and social functioning.

4.4.3 The Function of Restricted and Repetitive Interests and Activities in ASD

So what conclusions can be drawn about the function of restricted and repetitive interests and activities for people with ASD? According to the data presented here, there appears to be very little difference between the ASD group and the hobbyists in terms of why they engage in their interests; a wide variety of reasons

were given by both groups including factors inherent to the hobby (aesthetics, the general appeal of a subject); emotional factors (enjoyment, excitement, escapism); skill and intellect (problem-solving, knowledge-acquisition); social factors (sharing the interest with others, attending gatherings); impact on self or relationships (sense of achievement, building confidence, providing a substitute for social relationships) and so on. However, there are clues to suggest that motivating factors might be subtly different for the two groups. When asked about the "best thing" about their interest or activity, the ASD group were significantly more likely to cite reasons that could be coded as relating to the self or relationships than were the hobbyists. Though not evident from the data once it was coded, responses to questions about motivation did suggest a different feel about the ASD group - they made clear references to a role for their interests in building their confidence and self-esteem; finding their interests easier to cope with than social relationships; and using their interests to help them function; for example the young man who would take on the role of his favourite TV characters when out to help him manage social situations, or the man who talked to his stuffed toy as a friend and fantasised about "him" sorting out his work difficulties, the woman who was striving to learn as much as she could so as to be able to talk to people and make friends, or the woman who loved animals because "I can be near them and still think straight, whereas I can't with people". This quality of response simply wasn't evident for the hobbyists.

This suggests that for the ASD group these interests may have an important role in building and establishing self-esteem and confidence, developing a sense of identity and self-fulfillment and compensating for

difficulties in social relationships. It seems that these are individuals who cannot achieve a sense of identity or belonging via relationships; instead they may use their interests in this way. In the context of this interpretation, the reported distress when prevented from engaging in the interest could be viewed as a reaction to the loss of a valued activity. Hobbyists seem to attach less importance to their hobbies - they reported less distress if they couldn't do it, were less emotional when describing it, and in general seemed just a little bit less "attached". Their hobbies are important to them, but are part of a broader network of social relationships, family, work etc. Perhaps a hobbyist without this kind of network would report motivations more akin to those of the person with ASD; indeed the hobbyist who described his collection as "a substitute wife" also described a fairly isolated life.

These are all tentative interpretations of rather inconclusive data - separating out these factors would require a more detailed, qualitative approach to investigation and a larger sample.

4.4.4 Informant Data

With such a small sample, it is difficult to make much interpretation of the information provided by informants. Although there seemed to be little direct agreement between informants and their relatives, the broad conclusions regarding the positive function of these interests and the lack of strong evidence for obsessive or compulsive features remains. However, the fact that informants for both groups gave higher Y-BOCS scores suggests that they see these interests and activities as more of a problem than the individuals themselves. The

lack of agreement may have resulted from small discrepancies which had a disproportionate effect on the statistics owing to the small sample size; alternatively it may be simply that it is difficult to answer questions about somebody else's thoughts and feelings, no matter how well you know them.

4.4.5 Implications for Theories of ASD

The aim of this study was not to shed light on the theories of ASD described in the introduction section, however there are some comments that can be made:

- The participants were more able to report their thoughts and feelings than would be expected from the strong form of the theory of mind hypothesis.
- In terms of central coherence, there was some evidence that the interests and activities described by the ASD group were those that would benefit from a focus on detail - art (detailed copies), ornithology, computers; however there were others for which this was not the case - daydreaming about boats and Ireland, listening to music, a favourite stuffed toy. Besides, this still does not explain the range of motivations expressed.
- The executive function hypothesis is perhaps a little more relevant. Although these interests and activities certainly seem to be more than just a set of perseverative responses, the suggestion of a slightly obsessive or compulsive element, and the presence of other obsessional and compulsive difficulties may lend some support to the role of the frontal systems, which have been implicated in OCD (Baron-Cohen & Swettenham, 1997).

4.4.6 Generalisability

A further issue is that of generalisability - how far can the findings reported here be assumed to be applicable to other individuals on the autistic spectrum who are less able? There may be a developmental factor here - at a lower developmental level repetitive activities may serve a more basic need for stimulation; at a higher developmental level they and their functions become more complex and relate to more emotional and self/identity-related needs. It is not possible on the basis of this study to conclude that this is the case, or that the findings are indeed generalisable.

4.5 Clinical Implications

Rather than being a problem, the repetitive and restricted interests and activities of the people interviewed in this study seem to have, for the most part, positive functions with regard to the individual's self-esteem, identity and sheer enjoyment of life. This suggests that they are not something that it would be desirable or indeed ethical to eliminate by way of clinical intervention. The difficulty may not relate to the interests themselves, but rather to the lack of balance in the lives of people with ASD. Whereas hobbyists have friends, partners, occupations or other hobbies; many relatively able people with ASD lack this variety of sources for self-fulfillment and stimulation. These people are aware of their social difficulties and, it appears, are using their interests; either to help them cope with a confusing and stressful social world, or as a substitute for social activity and close relationships. After all, if one finds it painfully difficult to make "small talk", what better than to have a topic you can talk about with enthusiasm and ease? In addition, their interests serve the same sorts of functions as hobbies do for

people in the general population - they offer a source of pleasure, achievement, excitement and intellectual stimulation.

If this is indeed the case intervention might be aimed at building up the *range* of activities that a person with ASD has; perhaps using their interests to link them into a more social world, for example via clubs or societies. Some may even be able to use the skills they have developed to find employment. In this study, several people in the ASD group were either studying or working in fields related to their interest. These interests and activities, it seems, could be a useful entry point for the clinician who wishes to help someone with ASD develop more independence and work on their social skills.

The only valid rationale for intervening in these interests would be if they were interfering significantly in the person's ability to increase their independence and develop their social and occupational skills. The suggestion that there might be a slightly obsessive or compulsive element to motivation could mean a certain level of interference - the key would be a thorough assessment of the individual concerned. However, informants did report the interests as being more of a problem than participants themselves; and as it is often relatives who ask for help, consideration of their point of view is important.

Although it does seem that their interests are a positive part of life for the person with ASD, there is also evidence that they experience obsessions and compulsions. This is an area in which clinical intervention may well be desirable and appropriate, though careful consideration needs to be taken over its form.

There is some suggestion that pharmacological treatments for OCD may reduce repetitive interests and behaviours (Hollander, 1997), and one would need to consider the implications of this for the individual. For example, there could be an adverse effect on self-esteem, in which case it would be important to try and build up other sources of self-esteem. It might be worth trying cognitive-behavioural techniques; the experience of the author suggests that some more able people can grasp and implement basic cognitive-behavioural strategies.

4.6 Suggestions for Future Research

This study represents a different approach to that of others, as such there is scope to take it forwards:

- Replication with a larger sample and rectifying the methodological flaws listed earlier; perhaps focusing on fewer elements of OCD models and pursuing them in more detail.
- More detailed exploration of motivations via qualitative research. A particularly appropriate methodology might be one based on 'grounded theory' (Glaser & Strauss, 1965; cited in Pidgeon, 1996, pp. 75), which allows the researcher to generate theory that is 'grounded' in textual material, for example semi-structured interviews. Text from interviews is categorised and coded, placing emphasis on participants' own accounts and engaging in a process of 'constant comparison' (continually sifting and comparing elements as the research progresses) and 'theoretical sampling' (selecting new cases for their potential to extend or modify the emerging theory). Grounded theory is too complex to do justice to here; however it would clearly be an appropriate

methodology for extracting, analysing and making sense of the rich data contained within participants' responses to questions about their motivations.

- Investigate the applicability of these findings to less able people with ASD.
- Explore further the precise relationship between ASD and OCD, focusing on their actual obsessions and compulsions rather than on interests.
- Investigate possible treatments for obsessions and compulsions in ASD other than medication, including the use of cognitive-behavioural strategies.

4.7 Conclusions

The motivation underlying restricted and repetitive interests and activities in ASD seems more akin to that underlying hobbies engaged in by members of the general population than to OCD. These interests appear to be largely ego-syntonic in nature and to have a variety of positive functions for the individual. However, there is some suggestion of a slightly more obsessional or compulsive element to them than observed in hobbyists. Hence, although it would not be appropriate to apply a strong model of OCD to these behaviours, there may be a link at a milder level.

It is suggested that there are subtle motivational differences between people with ASD and hobbyists; namely that the interests of the former group have a stronger role in enhancing self-esteem and sense of identity, and helping them to cope in an otherwise confusing social world.

The implication of these findings is that clinical intervention should not focus on reducing these interests and activities, except in cases where there is clear evidence that they interfere with the individual's ability to function or cause undue distress; rather a more appropriate aim would be to aid the development of a wider range of confidence-building and hopefully social activities.

In the light of the methodological weaknesses of this study, these conclusions are tentative. It is hoped that further research will shed more light on the experiences of people with ASD, thereby increasing understanding of their perspective on the world and of how they can best be supported to make the most of their abilities and skills.

Section 5

References

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